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ABSTRACT

Addressed to docents, the manual presents general guidelines for making public tours of museums, historic buildings, and zoos more accessible to handicapped persons. Information on eight major disability groups is provided (mental retardation, learning disabilities, hearing impairments, visual handicaps, mobility impairments, cerebral palsy, mental illness, and severe communication disabilities), as well as on sensory and mobility changes that all older adults experience. It is noted that some disabled persons have needs that require the docent to rethink the basic structure of a program or substantially adapt the method of presentation. For each disability, related terminology is defined, emergency procedures noted, and specific suggestions offered for adapting the tour to meet the needs of the handicapping condition. For example, suggestions for adapting a tour for visually handicapped persons explore the following topics: evaluating the accessibility of the facility, introducing oneself, starting with a verbal orientation, offering assistance, speaking clearly and with enthusiasm, choosing an uncluttered route, including touchables in the tour, and using supplemental aids. A resource section presents a chart on epilepsy and how to assist a seizure victim, a list of agencies serving disabled individuals, and a selected bibliography. (JW)

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Part of Your General Public Is Disabled

Janice Majewski

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Part of Your General Public Is Disabled

• A Handbook for Guides in Museums, Zoos, and Historic Houses

Janice Majewski

Published for the Office of
Elementary and Secondary Education
by the Smithsonian Institution Press
Washington, D.C. London

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Foreword

Were we to ask our colleagues, "Would you deny a person access to your museums' collections or programs solely on the basis of his individual differences?" they would surely say "No, never." Yet for years this is exactly what we have unknowingly done to people with disabilities. We have set up, albeit inadvertently, physical and attitudinal barriers that have kept disabled people from enjoying the educational experiences our museums have to offer. Our multi-level buildings, low lighting, mauve-on-beige colored labels, and nonparticipatory tours are inaccessible to disabled people and implicitly refuse them entry into our buildings and programs.

This exclusion of disabled visitors has been due to neglect, not malevolence. The problem at first was not knowing there was a problem. Once we recognized it, we did not understand how to correct it. Now, however, we realize that changes must be made and that tools, such as this manual, are available to help guide those changes.

It is time for us to educate ourselves about disabilities and about how they affect people's lives. Replacing misconceptions with facts will enable us in the future to welcome a wider and more diverse audience—a goal that offers far-reaching benefits to us as well. Best of all, when we learn how to serve people with disabilities, we also learn how to better serve those we already include in our visitorship.

Robert McC. Adams
Secretary
Smithsonian Institution

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Manuals are often collaborative efforts, based on a combination of background information, first-hand experience, and collective common sense. This manual is no exception. It is the product of four years of meetings, telephone calls, theory-testing, and research. The list of people to thank is long and will surely have important names omitted. To all those who helped develop this publication, I am deeply grateful.

Editor and organizer *extraordinaire* Caroline Barnes offered her dual expertise as editor and special educator to this manual's great advantage.

The members of the manual's advisory committee met every month for a year between March 1982 and April 1983. They graciously shared their expert knowledge and contributed most of the information included in the sections on tour adaptations and emergency procedures. Many of them later reviewed drafts of individual chapters for accuracy of content. The members of the committee are listed according to the organizations they were affiliated with during the 1982–83 meetings.

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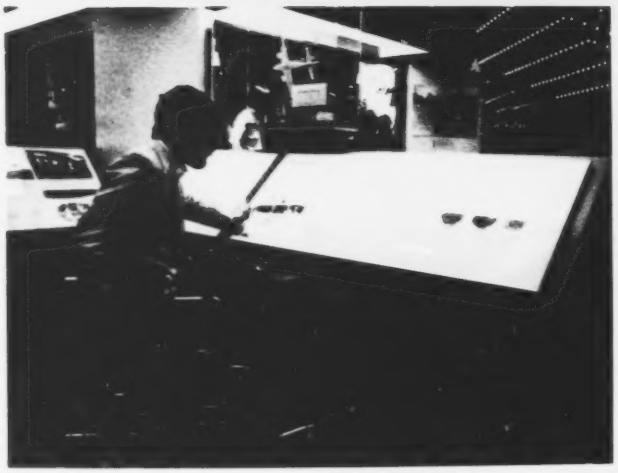
The docent speaks clearly and directly to a visitor who is hearing impaired. Photo credit: Dane Penland



A visitor who is a wheelchair user reads a label that is canted for use by people who are seated or standing. Photo credit: Laurie Minor

Touchable objects add a valuable dimension to tours for all visitors. Photo credit: Jeff Ploskonka

1

Introduction

Attitudes toward disabled people are complex and diverse, reflecting our own differences in background and perception, situational constraints, societal expectations, and variations among disabled people themselves. Yet one central, tragically wrong, assumption seems to pervade most of these attitudes: that disabled people are different from us more than they are like us, that their disabilities somehow set them apart from the rest of us.

(Frank Bowe, Handicapping America)

People with disabilities. We have long segregated them in the name of accommodating their special needs. But are they really so different that we must separate them out from the general public, devise special programs *only* for them, or tour them alone at off-hours in the museum? Must it always be *us* and *them*; or are we all part of the same general public that has a range of abilities and interests?

Labels have been devised to categorize people with disabilities for medical and educational purposes. The medical services offered to a person with cerebral palsy are necessarily different than those offered to a visually impaired individual; remedial educational programs necessary for a learning disabled child are not all appropriate for a child with a spinal cord injury.

However, the tendency has been to misuse these categories and to lump all of them into one general group called *disabilities*. We then assume that all people who are disabled are alike and, therefore, different from *normal* people. We're wrong. We need to realize that the norm is an arbitrary standard and that people's abilities fall on either side of that standard: the spectrum ranges from superior to low-functioning within an individual and among all people. There really is no such thing as *normal*.

You, as a docent, are used to "playing to your audience": your tour approach and depth of subject matter vary according to whether you have on tour a subject-area scholar, a teenager on spring break, a visitor with general interest in the collection, or all three together. You accommodate their individual needs in the context of your standard tour; you challenge your ability to interest and inform them on many different levels at once. You accept the fact that a program presented in a single way will never reach every person, and you act accordingly.

However, many docents balk at the idea of having disabled visitors on their tours. They say that they don't know how to tour disabled people, that they can't change their tour enough to make it a valid learning experience for persons with disabilities.

The truth is that most museum, zoo, or historic site visitors who are disabled are even more *like* than *unlike* those who are not disabled: they have varied interests, backgrounds, abilities, learning styles, and needs for accommodation. They will challenge your creativity and perception, and perhaps cause you to develop innovative approaches to your standard tour material.

It may sound as if common sense, sensitivity, and a willingness to adapt are all you need to successfully assist a disabled museum visitor. For the most part, this is true. So why have a training manual about people with disabilities?

One reason is that some people feel so uncomfortable around disabled individuals, and see them as so different from nondisabled people, that they fail to use common sense. A primary goal of this manual is to point out how much disabled and nondisabled people have in common and how often the adaptations that are appropriate for disabled persons work for nondisabled persons as well.

Secondly, several sources indicate that the more nondisabled people learn about disabled people, the more positive their attitudes are toward them. The purpose of this book is to inform you about different disabilities, to help you recognize the differences among them, and to make meeting people who may be different from people you've toured before more enjoyable. Having a disabled person join your tour does not have to be a negative experience—quite the opposite, it can be an extraordinary opportunity to learn how to effectively reach a wider segment of the general public.

Finally, some disabled people have needs that will require you to rethink the basic structure of a program or substantially adapt your methods of presentation. You should know *when* and *how* to make more drastic changes and how to evaluate your success with them.

This manual presents general guidelines (not definitive answers) for making disabled people welcome members of your *regular* tour groups. It offers suggestions on what to do when someone who is disabled arrives unexpectedly for your tour and demonstrates how to subtly assist a disabled person without embarrassing him or making him the center of attention. Most importantly, the manual offers ideas for adapting your tour so that your museum, zoo, or historic site becomes more accessible to *everyone*.

The goal of this book, therefore, is to encourage you to make your programs so generally accessible that a disabled person won't need to ask for additional assistance, and you won't have to frantically thumb through a manual to figure out how to give it.

The manual presents eight major groups of disabilities that people may have: mental retardation, learning disabilities, hearing impairments, visual handicaps, mobility impairments, cerebral palsy, mental illness, and severe communication disabilities. There is, in addition, a short chapter on sensory and mobility changes that all older adults experience. Though the disabilities are presented as distinct categories, there is much overlapping, particularly where older adults are concerned; people may have several mild disabilities or one mild and one severe disability.

Each chapter describes variations and degrees of individual disabilities and how they affect people. It is vital to recognize that a person who is hard of hearing has some very different needs from someone who is deaf; and that someone who lost his hearing at birth has needs that differ from someone who is gradually losing his hearing at an advanced age. There is always a wide range of abilities that must be taken into consideration.

The manual also presents practical information to aid you in planning and delivering your tour, handling emergency situations, and recognizing and working with the various assistive devices that disabled people might use. These do not represent the *only* approaches. Rather, they offer some new ways of looking at materials and techniques.

Finally, the manual offers a resource section which includes detailed information on seizures, agencies that serve disabled individuals, and a bibliography for further reading.

A Note on Terminology Used

As with any minority group movement working to reverse years of discrimination, the disability rights movement is still grappling with the terminology used to refer to people who have disabilities. In this manual, the terms used are those most widely accepted, most descriptive, and least stigmatized. For this reason, the term *disabled* rather than *handicapped* is used (except when in quoted material or as part of the preferred umbrella term *visually handicapped*). In addition, each chapter includes a section on acceptable and unacceptable terms that will help you feel comfortable about saying the *right thing* to and about disabled persons.

The other choice in terms relates to museums. The information presented in this manual is meant to be applicable to situations in museums, historic buildings, and zoos. Rather than listing all of these each time one or the other is mentioned, the word *museum* will be used as the generic term representing all three.

References and Sources

Specific references to sources are located at the end of each chapter and are cited by page number and identifying phrases. A selected bibliography for the entire manual (organized by chapter) will be found at the end of the book.

Reference Notes

p. 1 "ATTITUDES TOWARD DISABLED PEOPLE": F. Bowe, *Handicapping America: Barriers to Disabled People* (New York: Harper & Row, 1978), pp. 108–09.

p. 1 THE NORM IS AN ARBITRARY STANDARD: United States Commission on Civil Rights, *Accommodating the Spectrum of Individual Abilities* (Washington, D.C.: U.S. Commission on Civil Rights, 1983), pp. 87–93.

p. 2 SEVERAL SOURCES INDICATE: Ibid., p. 43.

2

People with Mental Retardation

"I do have some feelings. I have feelings for myself; I got pride and dignity in me. . . . Really!"

The person who made this statement obviously has self-respect and the ability to communicate his understanding of human emotions. He is also trying to change how others perceive him, and to convince them that he is a real and worthy individual. This speaker is retarded. He realizes that many nonretarded people believe that he has the feelings of a child, little ability to think, and little reason to be proud of himself. Most people, in fact, so underestimate how much a retarded person can learn and comprehend that *they* become the greatest handicap a retarded individual faces.

From the times of Greeks and Romans, people have had misconceptions about retarded individuals. Over the centuries, they have been thought of as monsters, jesters, innocents, menaces, and sexual molesters. Many societies wanted retarded persons killed or at least segregated in institutions on the outskirts of town, where they would not be threatening or even visible.

Although we may believe that we have progressed beyond such prejudices, ignorance about this disability persists. In 1985, a businessman leading a court battle to stop the establishment of a group home for retarded adults in Cleburne, Texas, said, "If they [one of the residents] got out in the street, they'd get run over. There's no place for these people there. They should be out on the edge of town, where they can have room to run around."

Archaic attitudes still overpower education. In some ways, our educated society really isn't so educated. Retarded people continue to be handicapped by those who are not retarded.

Description of the Disability

The National Association for Retarded Citizens describes a retarded person as "one who . . . from childhood develops consistently at a below average rate and experiences unusual difficulty in learning, social adjustment, and economic productivity." Although figures vary, the President's Committee on Mental Retardation estimates that between one and three percent of the United States' population (approximately two to six million people) is retarded.

There are approximately 250 to 300 known prenatal, paranatal, and postnatal causes of mental retardation, including: genetic factors, maternal rubella, head injury during birth, prolonged or shortened labor, child abuse, and lead poisoning.

Although genetic factors are believed to cause only between fifteen and twenty-five percent of mental retardation cases, the common physical characteristics of one genetically caused form of mental retardation, Down Syndrome, are often mistakenly generalized to all retarded individuals. A person with Down Syndrome is likely to have some or all of the following features: a round, flat face; small ears that are set low on the head; slanted eyes; a short, broad neck; and relatively short feet, hands, and fingers. It is fairly easy to identify people with Down Syndrome by their appearance. However, the majority of retarded persons do not have these characteristics and do not look any different from persons who are not retarded.

Of all those labeled as mentally retarded, the great majority (eighty-nine percent) are *mildly* retarded. They can develop enough academic as well as job-related skills to work in competitive areas of employment and acquire sufficient social and communication skills to

live independently. In fact, many are not even recognized as retarded once they leave a school environment; they successfully blend in with others in their communities.

Moderately retarded individuals (six percent) have more difficulty developing academic, job-related, and social skills but are still able to work in some competitive or sheltered employment situations and to live either independently or in supervised group homes.

People who are *severely* retarded (3½ percent) can learn to communicate and to care for themselves on a basic level but may have serious speech, language, and/or motor disabilities. They will probably develop few, if any, academic skills and will, most likely, live and work in closely supervised situations. However, some people with this degree of retardation are able to work successfully in competitive, unsupervised employment.

Profoundly retarded people (1½ percent) are the most severely disabled retarded people. They are also the most likely to have additional disabilities such as mobility impairments, emotional disturbances, and seizures. Individuals who are profoundly retarded may develop some communication skills but will almost always need to live in a highly controlled environment with attendant care. (Severely and profoundly retarded persons are often grouped together because their ability levels are so similar.)

Therefore, the great majority of retarded persons live and work independently and very successfully in the general community. These individuals are likely to visit your museum on weekends (because they work during the week) with friends and/or family members. They might take your general highlights tour and would benefit by some adaptations that will be described later in the chapter.

Effects of the Disability

Retarded persons, like everyone else, learn best by experience. They benefit from having objects and concepts related to their personal lives. Retarded people have difficulty learning without direct teaching, so it is essential that new ideas are specifically introduced, taught, and reinforced. Many retarded people's experiences have been limited by their living environment (e.g., institutions), overprotective parents and teachers, and others who have decided *for* them what is most appropriate to learn. Therefore, it is often difficult to fully evaluate whether a person's level of comprehension is a result of poor learning ability or lack of exposure.

Most people who are retarded progress through the same stages of intellectual and emotional development as people who are not retarded. The difference comes in the speed with which they reach new stages and the level of development within each. Whether due to a lower degree of development or a deprivation of environmental stimulation, retarded people have some common difficulties in social and academic situations.

Many retarded people have difficulty comprehending abstract concepts and concrete ideas when taught through abstract means. Unillustrated lectures, even those on such concrete subjects as animals, probably will not fully reach this audience. Verbal explanations are just not as effective as hands-on experiences. Participation, demonstration, and an effort to relate concepts to daily life are necessary to help retarded people understand topics. Once there is an initial understanding of a concept, it is necessary to reinforce it through repetition and varied applications. Many retarded persons have poor memory skills; the more often something is stressed, the more likely it is that real learning will occur.

Generalizing and applying newly learned material to other, similar situations are also difficult for a large number of retarded persons. For example, a retarded person might not see the similarity between a school and a museum, and therefore would not realize that many of the rules that apply in a school (e.g., not to run) apply in museums also. Some retarded people will learn a rule and apply it indiscriminately or inappropriately. Therefore, retarded visitors need assistance in making generalizations and understanding where and when to apply them. For instance, it would make the point more clearly and effectively to preface a warning to a retarded child about not running in museums with a statement that museums are like schools. That could be followed by a reinforcing statement: "The things that we keep in museums are very important. If we run, we might break one of these things. So, we cannot run in museums."

Another area that frequently causes problems for retarded persons is language development. Their receptive language (what they understand) is often more developed than their expressive language (what they say or write), but both are developmentally below the levels of most people who are not retarded. Therefore, tour vocabulary needs to be carefully explained and demonstrated. You should speak slowly and clearly, avoiding long, complex sentences, idiomatic expressions, or words with double meanings. Information that comes completely through the spoken or written word must be made more digestible; otherwise it will overwhelm.

Retarded people, if overwhelmed by information, are likely to lose interest in trying to follow what is said. They also tend to be easily distracted by outside stimuli. Because many retarded individuals have shortened attention spans, most sources recommend that programs be limited to thirty minutes. This estimate may not be true for every individual and should be used only as a guideline and adjusted as appropriate.

Because retarded people have problems with comprehension and are frequently told that their responses are wrong or inappropriate, many have low self-esteem and anticipate failure. They therefore tend to say "yes" to everything to gain approval and to look to nonretarded people for answers, guidance, and directions. They often underestimate their abilities and avoid challenges that they feel are too great, or they perseverate on simple tasks—enjoying the success and fearing change or failure. It is not that retarded persons do not become bored with tedious tasks, but rather that they prefer the security of them. If retarded people can be guided through the task of successfully adapting skills used in one area and then using them in others, they might be willing to take on new responsibilities.

Some retarded individuals have other disabilities as well. Speech impairments, mobility impairments, hearing impairments, visual handicaps, emotional disorders, and seizures sometimes accompany mental retardation. Depending on their severity, these additional disabilities may complicate problems caused by retardation. (For additional information on these other disabilities, see the appropriate chapters. Refer also to the Emergency Procedures section of this chapter and the Resources section at the end of the manual on what to do if someone has a seizure.)

Education and Training

Educational goals vary from developing academic abilities of mildly and moderately retarded persons to developing self-care and independence skills for severely and profoundly retarded individuals. Educational settings range correspondingly from total mainstreaming in a regular school to complete institutionalization in a residential facility. Placement depends on such factors as degree of retardation and the attitudes of parents and school officials.

Most mildly retarded persons are mainstreamed either full- or part-time in regular classrooms but receive some specialized instruction in resource rooms or special education classes as back-up. Some mildly retarded students may be primarily based in a special education classroom, and then mainstreamed in regular classrooms for certain subjects such as physical education and art.

Children who are more severely retarded are most likely to attend special schools, or special classes in regular schools. A small percentage live and attend school in residential institutions. The latter option will become, in the future, less of a choice as the government moves toward closing large, multi-bed facilities and dividing populations among small, family-like group and foster homes.

When retarded children become adults, they usually move from academic study to vocational training. Depending on how severely disabled the student is, he may be placed in a work-study environment for competitive job training or become enrolled in vocational training for sheltered workshops.

Most severely and profoundly retarded persons may learn just enough basic care and social interaction skills to enable them to live at least partially independent lives while working in supervised workshops and living in supervised living facilities.

Living Situations

Living situations for retarded persons vary as much as educational settings do. At one time, almost all retarded people were housed in institutions outside cities and isolated from society. Often their needs were confused with those of mentally ill people and they were placed in facilities with them and/or prisoners. Other retarded persons lived at home, hidden and sheltered by embarrassed and, often, guilt-ridden parents. Today, advocacy organizations for retarded people are trying to eliminate segregation and to ensure that retarded individuals can grow up and live in the least restrictive and most integrated environment possible.

Therefore, more and more retarded individuals are living alone or with roommates, spouses, their own families, foster families, or small groups of disabled and nondisabled persons in houses and apartments in residential neighborhoods.

The ideal living situation allows the retarded person the greatest independence he can handle and the most contact possible with the nonretarded public. Inappropriate social behaviors and immature emotional responses develop more frequently in retarded people because they lack good role models than because of influences of the disability itself. Retarded persons can learn a great deal by simply being around people who are not retarded. Of course, the reverse is also true; people who are not retarded can learn from those who are.

Terminology

Mentally retarded This is the term used to describe an individual who does not learn as quickly or as much as people who are not retarded, and has difficulty meeting the social expectations that have been established as the norm.

Remember that disabled persons are individuals and do not move, think, or act *en masse*. Therefore, they should be referred to as *disabled people* not *the disabled*. People with mental retardation should be referred to as *mentally retarded people* or *retarded people*, not *the retarded*. Certain words and phrases evoke negative images of retarded people and should *never* be used:

feebleminded
mongoloid
mentally defective
mentally subnormal
re-tard
retardate
moron
idiot
imbecile
holy innocent
eternal child
a victim of . . .
suffering from . . .
afflicted with . . .

Adapting Your Tour

State Important Rules at the Start of Your Tour

This is especially important if you are touring a group of retarded students. You may want to relate these rules (e.g., do not run; do not touch objects) to rules the students have in school. If a retarded adult or child has come with family or friends, assume that he knows these rules and mention only those museum regulations you would normally state during your tour.

Provide Visitors with a Simple Floorplan

Indicate where you plan to go and what you will see. A simple floorplan or color-coded map with pictographs or photographs will help orient retarded visitors to the building and aid them in directing their attention to specific rooms or objects. Never single out a retarded visitor; give floorplans and other handouts to everyone in the group.

Select Areas That Are Low in Visual and Auditory Stimulation

Most visitors have difficulty filtering out background noise; retarded visitors may have an even harder time concentrating when there is competition for their attention.

Allow Extra Time between Exhibits

Wait for group members to gather and for the retarded individual to position himself at each new location before you begin speaking. If he arrives after the discussion has begun, he may not be able to pick up on the topic and could lose interest altogether. Make smooth transitions between exhibits; let people know that you are ready to move on and where you are going.

Allow Retarded People to Drop Out of the Tour

Some people may not be able to stay with the group until the tour is over but may be embarrassed about leaving early. If you don't want to shorten your tour, make an announcement at the start that people are free to leave whenever they like (provided this does not conflict with other regulations). If building regulations do not permit this, announce one or more "breaking points" from which tired visitors can be escorted by another docent to the starting or ending point.

Be Confident and Enthusiastic in Your Presentation

Let people know that you are the leader. If someone makes an irrelevant comment, either tie it into the discussion or politely cut it off. Be flexible; try to accommodate people's varied interests. Do not immediately dismiss questions as being off the point; sometimes poor language skills make a question seem tangential when it really is not.

Encourage Participation in Your Tour

Do not be offended, however, if retarded people do not become involved or do not appear to be paying attention. Remember that many retarded individuals are used to being told that their answers are wrong or that they cannot do things correctly. They may be hesitant to put themselves on the line or may temporarily have lost track of the subject and will be embarrassed if you call on them. Ask open-ended questions that have neither right nor wrong answers. Present multi-sensory, participatory tours where people are doing things to-

gether and individuals are not singled out. Commend participants when it is appropriate—honest, positive reinforcement will encourage further involvement.

Always Address Retarded Adults As Adults

Be respectful. Retarded adults need, want, and deserve to be treated in a manner appropriate to their chronological age.

Communicate Directly with the Retarded Individual

Do not speak to him through someone else. If you do not understand his question or comment, ask him to repeat it, or repeat what you thought he said and ask for clarification and correction. If you still do not understand, ask permission of the retarded person to get assistance from a friend or family member in the group.

Remind All Visitors to Handle Fragile Objects with Care

Do not single out retarded people when making this statement. However, if you are concerned about the dexterity of some individuals, pass around only nonbreakable objects or show breakable objects to one person at a time.

Make Information Easy to Understand

Break information down into small segments, analyze tasks and new information (assume that your audience has little or no experience with it), and teach directions and facts step by step. For example, if you want to discuss types of home lighting in Colonial America, establish several baseline facts before proceeding: what home lighting is like today; that contemporary home lighting is run by electricity; that Colonial America existed three hundred years ago (a very long time ago); and that lighting was very different then because people did not know how to use electricity. Then give some examples of specific types of lighting devices used at that time. In this way, you are offering bits of information that, when put together, should be understandable to people who have difficulty with language, memory, and sequencing.

Move from Specific to General Information

Talk about one or two objects first—how they are used, what their purpose is—and then relate them to the room or gallery. Discuss the objects in concrete rather than abstract terms and relate them to the daily life of the visitors. Carefully explain new terms, especially if they are descriptive of abstract ideas (e.g., Palladian elements or the style of the Impressionists). Use demonstrations, if possible. Repeat information in a variety of ways.

Summarize Frequently

End each segment of your presentation (e.g., each room or exhibition area) with a one- or two-sentence synopsis of the information just presented. In that way, you give closure to that area and are ready to move on to the next one.

Offer Pictorial Supplementary Material

Pretour or follow-up materials with clear photographs of orientation landmarks and exhibits will help retarded individuals feel comfortable in your museum or historic site, and later to remember information that they learned. (See the section on photographs in the chapter on visual handicaps.)

Practice Exercises

The most effective way to practice these exercises is to work them through with an individual who is mentally retarded.

Exercise 1. Take a careful look at your general tour. Analyze it for the presence of the following factors:

- amount and type of participation elicited from the visitors
- the number of times references are made to historical events without background information or familiar time markers
- the number of times abstract terms (without concrete definitions) are mentioned
- locations of presentations and how much visual and/or auditory background noise exists

Try to devise ways to change these aspects so that your tour will always be a bit more accessible to retarded visitors, even if you don't know they are taking the tour.

Exercise 2. In a room or exhibition, select three objects that you could easily relate to visitors' lives. Practice

talking about these objects in this way. Next, think of ways you could involve the audience in relating to each object. You could use teaching aids such as touchables and photographs or drawings of the object in their historical contexts. You could also use participatory teaching methods such as demonstrations of the object or method for creating it, role-playing, and a question-and-answer approach.

Exercise 3. Analyze your tour and find one main, concrete theme that ties it all together (e.g., use of color in paintings, the most exotic animals in the zoo, a day in the life of the resident family). Go through your entire tour focusing all of your discussion on this theme. Try to discover how many ways you can reinforce this theme and still maintain interest. If you could only visit three of the exhibits (as might be necessary with a group of retarded individuals), decide which would be the three most instructive and comprehensible.

Emergency Procedures

In an emergency, follow procedures already established for your building or institution. However, a mentally retarded person may require additional attention in a crisis. Here are some procedures to follow in addition to standard ones.

If the retarded person is injured:

- Carefully estimate the extent of the injury. Some retarded persons may either exaggerate or underestimate the extent of their injuries.
- Be clear when telling the person what is happening. A person who already has difficulty processing information will have even more trouble in a stressful situation.

If the building must be evacuated:

- Seek out the retarded individual and make sure he knows there is an emergency.
- Assist him in finding his way out of the building. Someone who reacts strongly to overstimulation might freeze in this situation.
- Give directions to a retarded person in several modes—auditory, visual (e.g., pointing in the direction of the exit), and tactile (e.g., lightly tapping his right arm to indicate moving to the right).

If the person has a seizure:

A seizure is a neurological malfunction involving an uncontrolled electrical reaction in the brain. This temporary change in functioning causes an unusual level of electrical energy to pass between cells, overloading part or all of the brain's system. A seizure may involve muscle convulsions, partial or total loss of consciousness, mental confusion, and loss of control of some bodily functions.

There are two types of seizures, convulsive and nonconvulsive. Convulsive seizures are easier to recognize and require more assistance. The primary characteristics of a convulsive seizure are a loss of consciousness and muscle jerks.

The most important thing to remember if someone has a convulsive seizure is not to panic—remain calm and follow these basic rules:

- Place a folded coat under the person's head to prevent him from hitting it on the floor.
- Try to protect the person from hitting objects or furniture around him but do not restrain him. The seizure must run its course.
- Loosen his tie or shirt collar and try to turn him on his side to keep his air passage clear.
- *Do not* put hard objects into his mouth or try to hold his tongue—he cannot swallow his tongue but he can damage his teeth or your fingers by biting down forcefully.
- Do not try to get the person to drink anything during or right after the seizure.

If possible, check the person's wrists or neck for medic alert identification. If he is wearing any, it indicates the presence of a medical condition that may be related to his present physical state. It may be necessary to contact trained personnel for further assistance.

For more complete information on convulsive and nonconvulsive seizures, see the chart provided in the Resources section at the end of this manual.

Reference Notes

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p. 5 THEY PREFER THE SECURITY OF TEDIOUS TASKS: Ibid., p. 128.

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3

People with Learning Disabilities

The great scientist, Albert Einstein, did not speak until he was three years old; until age seven, he had such difficulty using words that he silently formed every sentence before he said it. President Woodrow Wilson did not learn the alphabet until he was nine years old and did not learn to read until he was eleven. August Rodin, the French sculptor, was declared uneducable, and Thomas Edison called himself a dunce because of his difficulties with learning. Vice-President Nelson Rockefeller had so many problems reading that he memorized all of his speeches for fear of delivering them incorrectly. These men were all of superior intellect *and* learning disabled.

Rockefeller said of his disability:

I was dyslexic. . .and I still have a hard time reading today. I remember vividly the pain and mortification I felt as a boy of eight when I was assigned to read a short passage of scripture at a community vesper service and did a thoroughly miserable job of it. I know what a dyslexic child goes through. . .the frustration of not being able to do what other children do easily, the humiliation of being thought not too bright when such is not the case at all.

Dyslexia, a difficulty in learning to read, is one kind of learning disability. It, like the others, can cause tremendous frustration and low self-esteem for the individual, and confusion for his family, friends, and teachers.

Description of the Disability

The term *learning disabilities* is as confusing to many professionals as it is to laypersons. First of all, the disability is really a *them*, not an *it*: the term, introduced in 1963, is an umbrella for a collection of conditions that singularly or in combination affect an individual's ability to receive, integrate, and/or express information in either a written or verbal form. It is, for the most part, an invisible disability—difficult to diagnose and easy to misinterpret. Over the years, there have been as many as sixty terms to describe the disability; people today still debate the definition, the population, the possible causes, and the methods of remediation.

One of the accepted definitions of learning disabilities is that one given in Public Law 94–142 (the Education for All Handicapped Children Act of 1975):

'specific learning disability' means a disorder in one or more of the basic psychological processes involved in understanding or in using language, spoken or written, which may manifest itself in an imperfect ability to listen, think, speak, read, write, spell, or to do mathematical calculations. The term includes such conditions as perceptual handicaps, brain injury, minimal brain dysfunction, dyslexia, and developmental aphasia. The term does not include children who have learning problems which are primarily the result of visual, hearing, or motor handicaps, of mental retardation, of emotional disturbance, or environmental, cultural, or economic disadvantage.

This broad definition, which does not indicate degree of severity, covers a wide spectrum of learning problems and disallows only those that are primarily caused by other impairments or conditions. Learning disabilities, however, may exist alongside those learning problems that do result from the other conditions mentioned. You should note that one of the disabilities listed as *not* being related to learning disabilities is mental retardation. Sometimes people confuse these two disabilities and mistakenly use the terms *learning disabilities* and *mental retardation* interchangeably. These are two different disabilities; individuals who are learning disabled have different needs and abilities

than those who are retarded. (See the chapter on mental retardation for more information.)

The legislation, however, did succeed in further defining the learning disabled population by setting up criteria for inclusion in this group. To be considered learning disabled, a student must not achieve at a level commensurate with his age and ability level and must show a severe discrepancy between his potential and actual achievement in one or more of the areas of oral expression, listening comprehension, written expression, basic reading skill, reading comprehension, mathematics calculation, or mathematics reasoning. This discrepancy must occur in spite of appropriate education in these areas.

Because of the dispute over the definition of learning disabilities, it is difficult to establish the prevalence of this disability. Estimates for the number of learning disabled children range between one percent and thirty-five percent of the school-aged population; no estimates exist for adults, many of whom may have been either misdiagnosed or labelled as "those who just did not try hard enough." In 1979, the U.S. Department of Education set the number of learning disabled children at three percent of the total school population, but even this determination is not absolute. However, several sources state that it is reasonable to expect that at least a few children (more likely boys than girls) in *every* classroom have some degree of learning disability. Because the Rehabilitation Services Administration established in 1981 a category of "specific learning disabilities," there may be greater numbers of adults officially identified in the future as learning disabled.

Effects of the Disability

Learning disabilities are disabilities of perception; the individual often misperceives—visually, aurally, tactually—his environment. Sometimes people in his environment misperceive *his* abilities and disabilities as well.

A learning disabled person is generally of average or above average intelligence and shows a discrepancy between his intellectual potential and his actual achievement in specific learning areas. This lower achievement may be due to such problems as hearing words out of sequence, failing to see how two objects are alike or different, or not being able to remember more than the last three words of a sentence just spoken. A learning disabled person may be thought of as lazy, or may be accused of not trying hard enough, because his achievement is inconsistent from one academic area to another or in the same academic area on different days.

Every learning disabled individual is just that—an individual—with his own combination of conditions that add up to his disability. Therefore, every person has his own learning and behavioral characteristics. However, according to Bill R. Gearheart's *Learning Disabilities: Educational Strategies*, there are some characteristics that may appear more frequently than others. These are hyperactivity, hypoactivity, inattention, overattention and perseveration, lack of coordination, perceptual disorders, and memory disorders.

Hyperactivity. A hyperactive individual needs to move around a lot and has difficulty attending to one task for any length of time. A hyperactive person may not be able to stay through your entire tour. He may need to walk to other places, do other things, or leave and return to your tour at different intervals.

Hypoactivity. The hypoactive person is the opposite of the hyperactive one; he tends to be slow and difficult to motivate. This person may also drop out of your tour, finding it a strain to continue through the whole route.

Inattention. An inattentive person may or may not be hyperactive, but is highly distractible and has difficulty doing one activity for any length of time. Like the hyperactive person, this individual may need to move around. If he stays with your tour, his attention might wander.

Overattention and perseveration. An individual with these characteristics finds it difficult to stop paying attention to one object or activity. He may need someone to help him refocus his attention on something else. During a tour, this person may fixate on one detail of a painting or inappropriately repeat a response to a question several times. A student with this problem may work on a project to the point of ruining it because he cannot stop when it is completed.

Lack of coordination. A person with this characteristic may have problems with fine or gross motor control. For example, he may find it difficult to hold a pencil properly, use scissors, or pick up small objects (fine motor); or jump rope, erase a blackboard, or catch a ball (gross motor). Poor coordination may also be related to perceptual problems that cause the person to misjudge height or distance. In a museum, he may have difficulty negotiating through narrow or cluttered areas, or he may not want to participate in a crafts activity requiring cutting, beading, or pasting small objects.

Perceptual disorders. For a person with a perceptual disorder, information coming through auditory, visual, or tactual channels may be garbled even though

the sensory organs are functioning correctly. For example, the person may hear sounds or words out of order (e.g., *bakset* instead of *basket*), and may be unable to find an object in a cluttered background or to differentiate between two textures. People with these disorders may have trouble following verbal directions, locating a selected object in an exhibition, or making a tactile distinction between polished granite and poured cement.

Memory disorders. People may have either auditory or visual short-term memory disorders; they may forget what they heard or saw a few minutes earlier. An individual with this problem might have difficulty answering tour questions on material he has only just heard, or making a comparison between an object he saw earlier and one presently being discussed.

These are the most frequently occurring disorders in people diagnosed as learning disabled, but there are many others that may appear alone or in conjunction with them. (For a more complete list, see the supplemental section at the end of this chapter.)

Generally, then, a learning disabled person is someone who has difficulty processing information. His misperceptions often cause him to be disorganized, literal-minded, inconsistent or inflexible in his responses to situations, and/or unable to function well in a highly stimulating environment. His repeated failures combined with the attitudes of those around him may cause him to feel inadequate; he may develop a negative self-image and adopt a defensive stance of "I don't want to" instead of "I can't." Because of this attitude, he may have trouble associating with peers and teachers, which only serves to worsen his self-image. Learning disabilities can make daily life difficult and confusing. A learning disabled individual must constantly re-sort information and refocus his attention—tasks requiring enormous patience.

Some learning disabilities can be remediated during childhood; others may be circumvented by coping mechanisms or avoidance throughout adulthood. Many learning disabilities are never diagnosed, leaving the individual with a feeling of being "somehow less than a good, normal person."

Education and Training

At the elementary school level, there are basically three educational options for learning disabled students: the special school, either residential or day; the self-contained classroom; and the resource room/itinerant teacher program.

The special school offers a totally segregated learning experience away from the nonlearning disabled population. This is the least frequently used option. The self-contained classroom in a regular school is for students with severe learning disorders, possibly compounded by behavior problems, who attend some regular classes during the day but spend most of the time in their own special classroom. The most commonly used option is the resource room, where students—mainstreamed into classes all day—come on a regular basis for tutorial assistance in a particularly weak subject area or for basic skill remediation. If the school does not have a full-time resource room teacher, then an itinerant teacher may visit the students on a prescribed schedule.

At the secondary level, programs range from tutorials to work-study assignments. There are few self-contained programs for students above the elementary school level.

If the learning disabilities are not remedied by the end of high school, there are limited opportunities for college level assistance or vocational rehabilitation. Good college programs offer services such as tape-recorded texts, readers, and tutorial help as well as programs to develop study and self-organizational skills. Vocational rehabilitation programs, on the other hand, teach basic academic and social skills, offer therapy, and guide the person to his areas of strength. Unfortunately, learning disabled adults often have to identify, refer, and motivate themselves in order to receive vocational rehabilitation assistance.

Aids for Learning Disabled Individuals

Tape Recorders. Individuals who have dyslexia may use tape recorders to read books or to take notes during lectures. These individuals are eligible for recorded book services from Recordings for the Blind, Inc. and the National Library Service for the Blind and Physically Handicapped. People with auditory perceptual and auditory memory problems may also use tape recorders. By taping lectures, they can listen to the information again under quieter, less stressful conditions and thus understand more material.

Readers. Individuals with dyslexia may request assistance of someone to read printed material to them.

Terminology

Remember that disabled people are individuals and do not move, think, or act *en masse*. Therefore, they

should be referred to as *disabled people*, not *the disabled*. People with learning disabilities should be referred to as *learning disabled people*, not *the learning disabled*. Other terms evoke incorrect attitudes toward learning disabled persons and should not be used: a victim of, suffering from, and afflicted with. (For more information on specific terminology related to learning disabilities, see the supplemental section at the end of this chapter.)

Adapting Your Tour

Plan Ahead If Possible

If you know beforehand that one or more learning disabled people will be on your tour, try to find out what kind of disabilities they have and what assistance you should offer. This is particularly important if your tour includes a class of learning disabled students; you may be required to deal with a variety of learning disabilities all at once. In this situation, the teacher is your best resource. Find out what approach he recommends. If an individual identifies himself as learning disabled at the start of your tour, ask him directly how you can best assist him.

Keep the Tour Group Small

Some learning disabled people are easily distracted, and touring with a small group will help them focus on you and the exhibits. You may also find it easier to give tour members more individual attention when the group is small.

Shorten the Tour

Many learning disabled students have short attention spans. Try to present only the most interesting and important information, and change the pace if you feel you are losing the individual's or group's attention. However, if only one learning disabled person is participating, do not shorten the tour; give the person an "out" by stating that people are free to leave whenever they like (provided this does not conflict with museum rules). If people must be part of a tour group while at a site, arrange for a breaking point where another docent can lead those wishing to leave to the starting or ending point. Avoid directing the statement at the learning disabled participant. This "out" will allow him to leave the tour if necessary without fear of appearing foolish.

Establish Rules at the Start of the Tour

If your tour includes a school group of learning disabled students, welcome them first and then state the two most important rules clearly and succinctly. Try to be positive. For example, say "We are glad you are visiting the National Museum of American History. We have two very important rules you must follow. You must *always walk* in the building. You may *touch only* certain things here. I will tell you what you may touch." Be sure to stand between the children and nontouchable objects.

Map Out a Simple Route

Learning disabled people who have problems with directionality may need assistance in finding their way through a site, particularly if it is complex or maze-like. Plan a route through the site that is uncluttered and easy to follow. Have available a simple floorplan or color-coded map of the area using landmarks or pictographs to distribute to all members of the group (whether or not they are learning disabled) at the start of the tour. Also give verbal directions, including a description of the building and an outline of the route you will follow, using the map as reference.

Provide a Written Outline of the Tour

Offer it to all group members. Include photographs of the exhibition areas to be visited and such information as whether or not rest stops are included in the tour. (Orientation materials such as these should be sent to a school group ahead of time.) Make sure that all handouts are visually accessible and uncluttered. (See the section on printed materials in the chapter on visual handicaps.)

Select Well-Organized Exhibits

Learning disabled students who are easily confused by an overload of visual, auditory, or tactile stimulation may have problems in a museum. If possible, guide them in small groups to quiet, uncrowded areas of the building. Choose exhibits that are uncluttered and well organized visually and structurally. If a lengthy discussion or lesson has been planned, take the groups first to a separate room for the lesson and then go directly to the exhibit discussed. If possible, return to the first room for a summary of the lesson.

Check Exhibit Signs and Labels for Readability

Many learning disabled people have lower reading skills due to visual perceptual problems and so may have difficulty understanding signs and labels used in exhibits. This difficulty may be compounded by aesthetic touches such as small and unusual typefaces, letters set against a print background, and poor color contrast between background and type. You may wish to offer this information in a rewritten, easy-to-read format. (See the section on written material in the chapter on hearing impairments.)

Take a Multi-Sensory Approach

Because your tour may include learning disabled individuals with different and possibly conflicting needs, you may need to present complex information through several sensory channels. For example, the method for creating a photosilkscreen could be presented verbally, illustrated by a sequence of pictures, demonstrated, and finally recounted during a discussion of Andy Warhol's work.

Speak Clearly and at a Normal Pace

If you suspect that people are having difficulty understanding you, adjust the pace accordingly. Use short sentences, particularly when addressing people with auditory problems. Do not talk down to your audience; keep sentence structure basic but not childish. Also, do not depend on variations in voice pitch or tone to add meaning to your words. Many learning disabled people, when concentrating on understanding the words, miss the more subtle information communicated by inflection. For example, the positive statement "This is a fine thing you've done," said with a sarcastic tone and inflection may be difficult for some learning disabled people to appreciate.

Avoid Distractions

If you know ahead of time that there will be learning disabled people on your tour, avoid boldly patterned clothing and heavy or noisy jewelry. If possible, position yourself in front of a solid background when addressing the group.

Make Smooth Transitions between Exhibits

Some learning disabled individuals have difficulty changing activities abruptly. Let people know a minute or so ahead of time that you will be moving on to a new exhibit or room. For example, "In about two minutes, we will walk over to President Wilson's kitchen area." Then when the time comes, make the transition quickly and smoothly. Limit the number of unstructured periods during which tour members wander through exhibits.

Include Touchables and Props When Possible

This will increase interest and reinforce information that's presented verbally. Be sure to carefully identify those items that may be touched, especially if your tour includes a school group. In addition, be sure to instruct individuals on how to handle fragile objects.

Explain Carefully Any Difficult Terms and Concepts

- Make sure that technical terms and new vocabulary are carefully introduced and defined. Relate new words to familiar information if possible.
- Use vocabulary cards to reinforce learning of key words at the appropriate exhibits.
- Some learning disabled individuals have a poor grasp of calendar and historical time. If these concepts are to be included in the tour information, make sure they are carefully explained and demonstrated.
- If it is necessary to include abstract concepts in your tour, try to introduce them in relation to concrete examples. Relate abstractions to people's lives; use demonstrations and participatory activities to clarify abstract concepts whenever possible.
- When describing a procedure, limit the number of steps you give in sequence. When addressing learning disabled children, give one step at a time; for learning disabled adults, limit the sequence to three at a time.
- If you give directions (e.g., *to the left* or *in front of*), be sure to give them from the audience's point of view.

Avoid Embarrassing the Learning Disabled Person

- Wait for a learning disabled person to indicate he wishes to answer a question before calling on him. He may be hesitant to speak in front of a group due

to low self-esteem, poor speech, or delays in processing information.

- When you distribute supplemental handouts such as agendas and maps, be sure to give them to all participants, not just those who are learning disabled.
- If a learning disabled person says something you don't understand due to his poor speech, ask him to repeat it. If you still don't understand, suggest that you speak with him after the tour about his question or answer.
- If a learning disabled person clearly did not understand an exhibit, you may want to allow the group to stay in the exhibit for a few extra minutes and subtly make yourself available to the learning disabled person for questions.
- If someone on your tour becomes disruptive or responds inappropriately, take him aside as soon as possible and explain the problem; tell him that he must either stop his behavior or leave the tour. If a student in a school group misbehaves, ask the teacher to intervene.

Use Supplemental Aids

Written information. Materials related to the tour, such as program guides or agendas, brochures, catalogs, and scripts of audio and audio-visual programs can be useful supplements for many learning disabled people, especially those with auditory perceptual problems. Because many learning disabled people have lower reading skills, all materials should be written in a straightforward manner using simplified English, never "talking down" to the audience. Be sure to read all written handouts aloud at some point during the tour. (See the section on written material in the chapter on hearing impairments, and the section on printed materials in the chapter on visual handicaps.)

Verbal information. This is best for those learning disabled people with visual perceptual problems that make it difficult for them to read. Most likely, the information you present on the tour will be through live oral delivery, but this can be supplemented with tape-recorded information. Audio-taped, self-guided tours are good because they allow the learning disabled individual to pace himself, relax, and enjoy the exhibit if he is uncomfortable in a structured tour. A small tape recorder may be used to play taped versions of label texts and brochures.

Visual aids. Such visual aids as photographs and slides will assist individuals with visual figure-ground problems. For example, a photograph of an exhibit detail may help an individual observe its line, color, and structure more easily and later help him distinguish the detail in the context of the exhibit. A pointer or flashlight can be used to locate details in an art work or objects in a complex exhibition.

Practice Exercises

The following exercises are best practiced with a learning disabled adult who can critique presentations and help develop new approaches to exhibits.

Exercise 1. Working in pairs, practice using simple language to describe exhibitions and works of art to learning disabled individuals. While one docent describes an object or work of art, the other should listen for the following:

- high interest information
- length of sentence (short)
- sentence structure (simple)
- use of complete sentences
- synonyms for difficult vocabulary
- introduction/definition of new vocabulary
- tone of voice (try to eliminate a sing-song quality and overtones of condescension)

Exercise 2. Working in pairs, walk through the tour that you currently offer. List the major exhibits and/or concepts that are introduced during the program. Brainstorm with each other to develop at least two ways, using different sensory channels, that you could reinforce understanding of each topic.

Emergency Procedures

In an emergency, follow procedures already established for your building or institution. However, a learning disabled person may require additional attention in a crisis. Here are some procedures to follow in addition to standard ones.

If the learning disabled person is injured:

- Carefully estimate the extent of the injury. Do not rely completely on the person's own evaluation of his

injury; some learning disabled persons either exaggerate or underestimate the extent of their injuries.

- Be clear when telling the person what is happening. A person who has difficulty processing information under normal circumstances will have even more trouble in a stressful situation.

If the building must be evacuated:

- Seek out the learning disabled individual and make sure he knows there is an emergency.
- Assist the individual in finding his way out of the building. Someone who reacts strongly to overstimulation might freeze in this situation.
- Give directions to people in several modes—orally, visually, and even tactually, if necessary.

Supplemental Information

The following article was reprinted from *Steps to Independence for People with Learning Disabilities* with permission of the author.

Types of Learning Disabilities

by Dale Brown

Academic Difficulties.

Problems with learning basic academic skills. These include:

Dyscalculia—Inability to do math.
Dysgraphia—Inability to write.
Dyslexia—Inability to read.

Associated Reactions.

One part of the body moves involuntarily because of the movement of another part of the body: for instance, the left arm may move when the right arm moves or one arm may move when the head turns.

Auditory Perceptual Problem.

Trouble taking information in through the sense of hearing and/or processing that information. People with this problem frequently hear inaccurately. A sequencing or discrimination error can change the meaning of an entire message: for example, one might hear "I ran to the car," instead of "I rented the car." People with auditory handicaps frequently do not hear unaccented syllables. They may hear "formed" instead of "performed," "seven" instead of "seventy." Some auditory perceptual handicaps are:

Auditory discrimination problem. Trouble telling the difference between similar sounds, such as "th" and "f" or "m" and "n"; hearing "seventeen" instead of "seventy"; hearing an angry rather than a joking tone of voice.

Auditory figure-ground problem. Trouble hearing a sound over background noise, for example, being unable to hear the telephone ring when one is listening to the radio, or having difficulty hearing someone talking at a party when music is playing.

Auditory sequencing problem. Trouble hearing sounds in the correct order, for example, hearing "nine-four" instead of "four-nine"; hearing "treats" instead of "street"; hearing garbled music because the melody is perceived out of order.

Catastrophic Response.

An involuntary reaction to too many sights, sounds, extreme emotions or other strong stimuli. This may result in losing one's temper, becoming dazed or unaware of one's surroundings, or "freezing" for a short time.

Cognitive Disorganization.

Difficulty thinking in an orderly, logical way. People with this problem often jump to conclusions and have difficulty planning tasks.

Crossing the Midline.

Trouble with moving one's limbs across the center of the body. This could include: difficulty writing across a page, sweeping a floor or controlling a steering wheel.

Directional Problem.

Trouble automatically distinguishing left from right: learning north, south, east, west; learning the layout of a large symmetrical building.

Disinhibition.

Difficulty in behaving appropriately in an automatic way. This is a problem with the self-governing part of the brain that stops one from doing such things as laughing at the wrong time, talking aloud to oneself, coughing without covering the mouth. A disinhibited person might abruptly interrupt a conversation or talk aloud to himself in public.

Intersensory Problem.

Trouble using two senses at once or associating two senses, for instance, not realizing that the letter "d" which is seen, is the same as the sound "d" when it is spoken; being unable to listen to conversation and drive at the same time.

Memory Problem, Short-Term.

Trouble remembering: names, numbers, specific facts, what happened a few minutes ago. A poor memory makes academic success difficult.

Motor Problem.

Trouble moving one's body efficiently to achieve a certain goal. Some motor problems are:

Perceptual motor problems. Trouble performing a task requiring coordination because of inaccurate information received through the senses. This may result in clumsiness, difficulty in participating in simple sports, awkward or stiff movements.

Visual motor problem. Trouble seeing something and then doing it: learning a dance step while watching a teacher, copying something off a blackboard, throwing something at a target.

Auditory motor problem. Trouble hearing something and then doing it: following verbal directions, dancing to a rhythmic beat, taking notes in a lecture.

Perceptual Problem.

Trouble taking information in through one's senses and/or processing that information.

Proprioceptive Perceptual Problem.

Trouble knowing where one is in space. A person with this problem might not be able to tell the position of her limbs with her eyes closed.

Soft Neurological Signs.

Signs of central nervous system dysfunction that can be observed: staring, turning the head instead of moving the eyes, inability to look people in the eye, not holding the head straight, being easily startled.

Tactile Perceptual Problem.

Trouble taking information in through the sense of touch. Some tactile handicaps are:

Immature tactile system. People with this problem dislike being touched lightly, but crave pressure touch, such as being hugged hard or huddling with knees to their chest. Until the immaturity is overcome, tactile discrimination cannot develop.

Tactile defensiveness. Tendency to avoid being touched because of an immature tactile system.

Tactile discrimination problem. Trouble feeling the difference between similar objects, such as bond or regular typing paper, light or heavy sandpaper, silk or cotton, ripe or unripe cantaloupe.

Tactile pressure problem. Trouble judging the right amount of pressure needed to perform motor acts: holding an egg in two fingers without breaking or dropping it, tapping someone playfully rather than hitting them.

Vestibular Perceptual Problem.

Problem with one's sense of balance, for example, a tendency to lose one's footing on a curb.

Visual Perceptual Problem.

Trouble taking information in through the sense of sight and/or processing that information. Some of these are:

Visual figure-ground problem. Trouble seeing a specific image within a competing background: finding a face in a crowd, finding keys on a crowded desk, picking out one line of print from the other lines in a book. People with this problem cannot see things that others can see; to them the keys on a crowded desk are not there.

Visual sequencing problem. Trouble seeing things in a correct order, for instance, seeing letters or numbers reversed, seeing two cans reversed on a shelf of cans. The person with this problem actually sees the word incorrectly. He sees "was" instead of "saw."

Depth perception problem. Trouble perceiving how far away (or near) an object may be: for instance, you may

not know how close the fork is to your hand or how far to reach to put a glass of water on the table.

Reference Notes

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4

People with Hearing Impairments

Description of the Disability

Hearing impairments range from mild to profound. One hearing impaired person may be able to hear everything but very high-pitched sounds, while another may hear only the roar of a jet engine. Both are described as hearing impaired, but their needs are drastically different.

There are approximately 20 million *hearing impaired* people in the United States. Of this number, 19.6 million are *hard of hearing* (have some usable residual hearing) and 400,000 are *deaf* (have little or no usable residual hearing). Thirty percent of people over the age of sixty-five have some degree of hearing impairment.

Hearing impairments may be caused by genetic factors, illness, medication, injury, aging, and sudden or sustained exposure to loud noise. They may occur before or during birth (congenital) or any time thereafter (adventitious).

In a museum setting, perhaps the greatest problem a hearing impaired person will encounter is communication: hearing a tour, catching information given over a public address system, asking for directions. As Jack Gannon, a deaf historian, put it, "Deafness is two percent handicap and ninety-eight percent misunderstanding."

To illustrate this point, imagine that you come up behind a deaf man. Without getting the man's attention, you ask him for a match. The deaf man, of course, does not realize he is being addressed and does not turn around. You become annoyed and give him a dirty look as you walk away. Think of his confusion when he sees your expression.

Communication can be a serious problem for all hearing impaired people, complicated by misunderstandings and missed information. Patience on both sides is essential if good communication with a hearing impaired person is to take place.

The Hard of Hearing Person

Effects of the Disability

Range of Hearing Loss

There are four major categories of hearing loss: mild, moderate, severe, and profound. People who are hard of hearing generally fall into the first three categories. In other words, among people classified as hard of hearing, the extent of disability ranges from an inability to hear high-pitched, quiet sounds to an inability to hear most conversation unaided. In fact, a severely hard of hearing person without a hearing aid may just *begin* to hear sound at the loudness level of a motorcycle engine at close range.

Effect on Communication

Need for visual cues. Hard of hearing people are generally more dependent on visual cues than persons who are not hearing impaired; they watch facial expression and gestures and often speechread (lipread)—consciously or not—to fill in gaps. The amount

of visual cueing a person needs depends on the severity of his loss, how well he is able to use his residual hearing, and whether or not he wears a hearing aid.

Another factor that affects the need for visual cueing is background noise (e.g., crowd sounds in an exhibition hall) which can distract a hard of hearing person and make it more difficult for him to pick out a speaker's words due to the masking (covering over) of higher-pitched speech by lower-pitched background sound. If there is background noise in an area, you must be especially careful to face the hard of hearing person and to make sure that lighting is adequate for speechreading. (For more information on speechreading, see the section on deafness in this chapter.)

Ability to develop speech. Depending on the degree of his hearing loss and when it occurred, a hard of hearing person may have difficulty developing his speech. The longer the person has been hard of hearing and the more severe the hearing loss, the more likely he is to have speech problems; he may eliminate certain sounds or mispronounce words because he does not hear them correctly or at all (and thus has no feedback for self-monitoring), and he may have an unusual pitch or tone to his voice.

Adjusting to the disability. Hearing impairment carries with it a strong stigma. Although people who wear eyeglasses to correct visual impairments are accepted by society, the same is not always true of people who wear hearing aids to correct hearing impairments. Therefore, many adventitiously hard of hearing adults are very reluctant to admit that they are losing their hearing. As a result, they face the frustration of missed conversations and other information, and feel incompetent because of this. Many individuals, particularly older adults, will not even acknowledge the impairment and will strongly resent any reference to its existence. For these reasons, you should be very diplomatic when accommodating someone who is hard of hearing. If he identifies himself as hearing impaired, follow the suggestions for assisting him. If you *suspect* he is hard of hearing (because you notice that he tries to stay in front of the group, watches your face very carefully, requests that statements be repeated often, or asks questions that were already asked), then you should accommodate his disability without formally acknowledging it.

Education and Training

Most students who are hard of hearing attend public schools where they are mainstreamed into regular classrooms for all or part of the day. Depending on the extent of their disability, these students may use sign language or oral interpreters. (For more information on interpreters, see the supplemental section on working with interpreters at the end of this chapter.) In addition to classroom instruction, hard of hearing students may receive individualized speech therapy and tutorial help in a resource classroom to keep them at grade level academically.

Many individuals who become hearing impaired as adults do not acknowledge their disability or seek rehabilitative training. Those who do seek help usually attend classes in speechreading techniques and develop speech discrimination skills through the use of a hearing aid.

Aids for Hard of Hearing Individuals

Hearing Aid. A hearing aid is a miniature amplifier of sound. Although it increases the volume of sound, it does not make a hard of hearing person hear perfectly; it amplifies unwanted sounds as well as conversation and cannot eliminate the sound distortion caused by some hearing losses. In addition, it may fail to amplify certain frequencies enough for them to be heard by a person with little or no residual hearing at those frequencies. A person may wear one or two aids, depending on the severity and type of loss.

A hearing aid is composed of a *microphone* (to receive and convert sound into an electrical signal), an *amplifier* (to increase the signal's strength), a *receiver* (to convert the signal back to sound), an *earmold* (to channel sound into the ear canal), a *cord* (to connect the amplifier and receiver on body aids), and a *battery* (to provide the power source).

There are four main types of hearing aids:

1. *in-the-ear-aid.* The entire hearing aid fits into the ear canal and pinna (the external part of the ear).
2. *behind-the-ear aid* (sometimes called ear-level aid). All parts are contained in a case that rests behind the pinna; a small plastic tube connects the case to the earmold that fits into the ear canal.
3. *eyeglass aid.* All the mechanical components fit into the frame of the eyeglasses and are connected to the earmold by a small plastic tube.
4. *body aid.* The microphone and amplifier are contained in a case (usually the size of a small cigarette pack) worn in a pocket or pouch on a chest harness. The receiver (which looks like a button) is attached to the earmold and connected by a cord to the case. Some body aids have two receivers.

Individual Induction Loop Amplification System. An individual loop works with a person's hearing aid to am-

plify sound and to eliminate distracting background noise. The system consists of a loop of coated wire (worn around the neck) connected to an amplifier, which is connected to a hand-held microphone. When someone talks into the microphone, the sound is converted into an electrical signal and sent to the amplifier where it is made stronger. The amplified signal travels into the wire and creates a field of electric energy within the area encircled by the loop. The telecoil (turned on and off by a control called the T-switch) in the listener's hearing aid picks up the energy; and then the aid's receiver converts that signal back to sound. The only sound amplified, then, is the voice directed into the microphone. The sound received is clearer and of higher quality than that received through a hearing aid alone.

FM Broadcast System. An FM system sends its signal over a restricted, narrow-band frequency of an FM radio wave. The system consists of a directional microphone for you (usually worn around the neck) and a receiver/amplifier for the hard of hearing person (which temporarily replaces the individual's personal hearing aid). Like the induction loop system, the FM broadcast system cuts down the amount of background noise and gives higher quality sound. (This same equipment is used with classes of deaf children. Because it helps children improve their speech discrimination skills, it is also called auditory training equipment.)

Amplified Telephones. The amplifier can be built into the telephone handset or attached to the telephone receiver or body. It increases the volume of sound received by the listener. There are also amplifiers which increase the sound of the telephone ring. Public telephones with blue grommets (the pieces of rubber shielding the cord where it attaches to the receiver) are compatible with hearing aids that have telecoils. (They work the same way as the induction loop.)

The Deaf Person

Effects of the Disability

Range of Hearing Loss

Deaf people are considered to have a profound hearing impairment if they cannot hear a sound quieter than most music played by a rock band. This means that they do not hear any sounds quieter than a rock band. In addition, many people who have profound hearing losses have residual hearing only in the very low frequencies. Therefore, even with amplification they cannot hear many conversational speech sounds. One standard text describes deaf people as "those who do not have sufficient residual hearing to enable them to understand speech successfully, even with a hearing aid, without special instruction."

If a deaf person wears a hearing aid (many choose not to), he may be able to tell if sound is present and to discriminate voice inflection and intonation, sentence length, word length and number of syllables, and some speech sounds. This auditory information is used to supplement visual information (the main receptive mode) provided by one or a combination of the following: speechreading, sign language, fingerspelling, facial expression, gestures, mime, and cueing.

Effect on Communication

Deafness creates a major barrier to communication with hearing people. The deaf person must rely on his speech and speechreading abilities, on message writing, and/or on the help of an interpreter. Reception of communication is difficult for both congenitally and adventitiously deaf persons; expression of communication is generally much more difficult for the congenitally deaf individual.

Speechreading. For most deaf people, the main mode for receiving information is visual. Because the majority of hearing persons (and many hearing impaired people) do not know sign language, a deaf individual must usually speechread to receive communication directly from another person. Speechreading is a difficult skill to master and to speechread well, a person needs certain conditions: good lighting, close proximity to the speaker, a clear view of the speaker's mouth, good articulation by the speaker, a knowledge of the context of the conversation and the vocabulary used, and an ability to differentiate words that look alike (e.g., fifteen and fifty). In general, familiar phrases and sentences are easier to speechread than single words or unfamiliar phrases.

The age at which a person becomes hearing impaired affects his ability to speechread in different ways. A congenitally deaf adult, for example, may have years of practice in speechreading, but lacks sufficient vocabulary or English syntactic skills to understand all that he is seeing. The adventitiously deaf individual has learned to depend on hearing rather than seeing words and must change his whole approach to communication, but he has a solid language base to work from. Comprehension through speechreading, then, depends on a combination of specific conditions and individual abilities and is not a reflection of intelligence. Speechreading is a difficult skill requiring good concentration and the ability to quickly perceive a sentence as a whole. Not everyone can master it or depend on it as the sole source of information.

Developing speech. Expressive communication through speech and English (as opposed to American Sign Language) is often easier for the adventitiously deaf individual (especially if he lost his hearing as an adult) than for the congenitally deaf person. "Practically all of the initial learning experiences of young hearing children are acquired through the auditory channel, saturated as they are with words and spoken language from every direction, including radio and television. This constant verbal bombardment is not taught but absorbed." As a result "the deaf child is at a distinct disadvantage from the beginning, since there is an absence of the sound of daily living.

The congenitally deaf person must learn speech and language in a highly structured fashion, without the benefit of ever having heard conversation or the ability to monitor his own pitch, articulation, and pronunciation. Deaf children learn speech visually and tactually: they watch how sounds are formed with the lips, teeth, and tongue, noting how such sounds feel in the back of the throat or in the nose. Putting together several sounds to form a word takes a concerted effort and much practice. Feedback on performance is usually provided by someone else—someone who can hear how it all sounds.

Many congenitally deaf people never develop speech that is intelligible to hearing persons unfamiliar with deafness. Knowing that their speech may not be precise or their voice quality very clear, many deaf people choose not to speak at all—particularly with hearing individuals.

Acquiring language skills. English language skills are also difficult for congenitally deaf people to develop; they miss the usual childhood bombardment of language, the continual informal input of how our language is structured. For them, every rule must be learned, every exception must be memorized; they cannot depend on structuring sentences by the "it-sounds-right" rule. Consequently, many deaf people never completely master our complex language in spoken or written form or develop good reading skills; therefore, they do not develop English language abilities commensurate with their intelligence or level of accomplishment.

Education and Training

Deaf children attend either special schools (day or residential) or special classes in regular schools. Some deaf students are mainstreamed into regular classrooms, usually with the assistance of an interpreter.

There has long been debate over how deaf people should learn to communicate. Often called the "oral-manual controversy," the dispute centers around whether an individual should learn to speak (using his residual hearing and speechreading ability to the exclusion of sign language) so he can function in the hearing world; or whether he should communicate by whatever method or methods are easiest for him, including sign language (e.g., American Sign Language also known as ASL or Ameslan, Signed English, or Signing Exact English also known as SEE II), fingerspelling, speech, gesture, mime, writing, and a combination of all of the above called total communication. This controversy has greatly influenced educational methods for nearly two hundred years, causing the establishment of oral schools and manual schools. Strictly oral schools do not allow students to use any form of manual communication; manual schools require its use. A few school systems around the country use methods that fall between these two, such as cued speech—a system in which manual cues serve as an aid to speechreading, and the Rochester method—a system in which fingerspelling everything that is said aids speechreading. (For more information on communication, see the supplemental section on communication modes at the end of this chapter.)

The adventitiously deaf adult (if he acknowledges his disability) may attend classes at a rehabilitation center to learn sign language and/or develop speechreading skills. Depending on the degree of loss, he may use a hearing aid to assist his speech discrimination skills.

Aids for Deaf Individuals

Hearing aids. Many deaf people do not find hearing aids useful and choose not to wear them. However, some deaf people find that with hearing aids they can gain information about sound and their environment. For example, they may be able to tell if someone is speaking; the duration, intonation, and inflection of sentences; and frequently the pitch and quality of their own speech production. (For more information on hearing aids, see the section on aids for hard of hearing individuals in this chapter.)

Telecommunications Device for the Deaf (TDD). This new technology has replaced teletypewriters (TTYs). Based on the same principle as a TTY, a TDD is a device that converts the standard aural telephone into a visual communication system. Usually consisting of a typewriter-like keyboard and a coupler in which to place the telephone receiver, the TDD sends high-pitched beeping signals (corresponding to the typed letters in the message) over regular telephone lines. The same kind of machine at the other end receives the signals and converts them back into letters, making this a written instead of spoken form of communication. TDDs are now very small and portable, allowing a hearing impaired person to make telephone calls when traveling outside the home.

Alerting devices. Alerting devices activate lights, strobes, or vibrators to inform deaf people of incoming telephone calls, visitors knocking at the door or ringing the doorbell, fire or smoke, a crying baby, and to wake them up in the morning.

Hearing ear dogs. Hearing ear dogs provide basically the same services as alerting devices. They are trained to alert their owners to everyday sounds and situations.

Terminology

Hearing impaired The general term used to describe people who have any degree of hearing loss, sometimes used synonymously with the term "hard of hearing."
Hard of hearing The term used to describe people who have usable residual hearing.
Deaf The term used to describe people who have little or no usable residual hearing.

Remember that disabled persons are individuals and do not move, think, or act *en masse*. Therefore, they should be referred to as *disabled people*, not *the disabled*. People with hearing impairments should be referred to as *hearing impaired people*, not *the hearing impaired*. Certain phrases that are frequently used to describe hard of hearing and deaf persons evoke inappropriate responses of pity or awe. Therefore, do not refer to a hearing impaired person as:

deaf and dumb
deaf mute
stone deaf
dummy
suffering from. . .
afflicted by. . .
a victim of. . .
sentenced to a life of. . .
almost normal
superhuman
overcoming insurmountable odds
courageous

Adapting Your Tour

Evaluate the Accessibility of the Facility

Try to make your museum as accessible as possible to hearing impaired visitors. Look over the facilities and identify areas that might present problems. If you cannot correct these problems, consider making changes in your programs such as planning an alternate route, selecting different exhibits, or preparing supplemental aids. Evaluate the following:

Lighting. Deaf and hard of hearing people require good lighting conditions for speechreading, watching an interpreter, and observing facial expressions and gestures. Evaluate lighting conditions in your museum and try to select exhibits and routes that are adequately lighted. If possible, avoid lighting that is too bright or dim, or directed in such a way that it would fall into the eyes of a hearing impaired member of the audience. If lighting conditions are poor but the exhibit is an important one, include it anyway and consider the following suggestions when addressing the group:

1. Position yourself so that you (rather than the hearing impaired person) are facing the light source. Stand close to the hearing impaired person.
2. Use display case lighting to supplement other lighting. Face the case or stand perpendicular to it. Never stand with your back to an illuminated display

case; you will be silhouetted by the light and even harder to see.

3. Find a well-lighted area to discuss the exhibit before or after its viewing.

4. Supplement verbal information with printed information related to the tour (e.g., an exhibit catalog, commentary, or floor plan with arrows pointing to specific areas).

Signs and Labels. Many congenitally deaf individuals have lower reading skills and may have trouble comprehending museum labels, brochures, and signs—especially if the language used is complex or the vocabulary difficult. You may wish to offer this information in a booklet using an easy-to-read format or to anticipate questions concerning information that is presented in printed form.

Background Noise. The everyday noises of museums (sounds of visitors, equipment, movie soundtracks) can greatly interfere with a hearing impaired person's ability to follow your tour delivery. Try to select exhibits that are located in quiet areas of the museum. If you can't find a quiet place, the hearing impaired person will need supplementary printed materials or an individualized amplification system (e.g., an induction loop or an FM transmitter) that cuts down the noise.

Arrange for an Interpreter If Possible

If a deaf individual plans to participate in your tour and requests the services of an interpreter, find out whether he needs an oral or sign language interpreter. Then try to locate a professional who has the appropriate skills and who holds certification from the Registry of Interpreters for the Deaf (RID). Arrange to meet with the interpeter about fifteen minutes before the tour to discuss content and any questions either of you might have. (For more information, see the supplemental section on working with interpreters at the end of this chapter.) If an interpreter is not available, try to provide good speechreading conditions, a script of tour information, and explanatory label text.

Create Good Conditions for the Interpreter

- Allow time for the interpreter to move to the front when you arrive at an exhibit.
- Make sure the interpreter stands in front of a solid background under good light.
- Stand so that the object you are discussing is between you and the interpreter. The hearing impaired person should be able to have you, the object, and the interpreter in his line of sight. If you are discussing a room or a very large object, try to stand close to the interpreter so you are both in the hearing impaired person's line of sight.
- Don't compete with the interpreter if you know sign language; use your signing skills before or after the tour.

Facilitate Speechreading When Delivering Tour Information

- Maintain eye contact and try not to move around or turn your back to the audience while addressing hearing impaired individuals. Don't cause them to turn their backs to you. If you direct them to an object behind them, make sure they turn back to you before you begin describing it.
- Do not talk when traveling between exhibits. After you reach an exhibit, let the hearing impaired individual move to the front of the group before you begin speaking.
- Try not to talk at the same time you point to, hold up, or pass around an object. The hearing impaired person may have difficulty speechreading and observing the object at the same time.
- Always repeat questions from the audience. A hearing impaired person may not be able to speechread other tour members, particularly if they are positioned behind him.
- Keep your hands and hair away from your mouth. Long hair can fall forward and obscure the side view of your mouth.
- If you are a full-mustached or bearded man, you may be difficult or impossible to speechread. Instead of shaving, make sure that you maximize your audience's ability to speechread by following the suggestions above and make supplementary printed materials available.

Shorten the Tour and Cover Less Material

Plan for a *maximum* tour time of 1½ hours (no longer than one hour is preferable). Speechreading and following an interpreter can cause eye strain, particularly if the lighting is poor. Cover less material than you normally do during your tour, and allow time for looking and asking questions before moving on to the next exhibit. Remember that hearing impaired people cannot speechread or watch an interpreter and look at an object at the same time.

Speak Clearly and in a Normal Tone of Voice

If your speech is rapid or if you mumble and run words together, even the best lighting and amplification will not make your presentation more understandable. Slow your speech slightly (without exaggerating speech sounds) and articulate. Don't speak louder unless asked to do so (and then don't shout). Use natural facial expression and gestures, but limit large arm and body movements.

Explain Difficult Terms and Concepts

- Use vocabulary cards and point out pertinent labels to emphasize the visual form of words that are difficult to speechread.
- Repeat important concepts. Use more than one example to explain or illustrate them.
- Avoid using idioms and jargon; they are hard to decipher when speechreading and can be difficult for people with language problems to understand.
- Avoid vague terms such as *this* and *that* when describing details of exhibits. The hearing impaired individual may be looking at you (not the object) and will seek out the detail when you are finished speaking.
- Try to discuss ideas in concrete terms. If an abstraction must be used, relate it to something concrete—preferably something that the visitor is familiar with. Anecdotal information always strengthens a point.

Encourage Participation by Tour Members

A discussion format will give you feedback concerning the visitors' comprehension of the material presented. However, deaf visitors may be hesitant to speak out during your tour, so be positive, give them plenty of time, and encourage questions and comments. Repeat questions and answers, especially if there isn't an interpreter present, and always try to identify the speaker. If you do not understand a question, ask the person to repeat it or wait for him to request the interpreter's assistance. If you have no interpreter and cannot understand the repeated question, ask the visitor to write it down.

Use Supplemental Aids

Amplification Systems. There are several kinds of amplification systems available for room and individual use. These include:

1. loop induction system (room and individual use)
2. FM broadcast system (individual system)
3. AM broadcast system (room system)
4. infrared system (room system)

For a room system, the room is outfitted with a transmitter and the individual wears a receiver; for an individual system, one individual wears or holds a transmitter and the other a receiver. If your museum has an amplification system, make sure you know how it works and what to do if it breaks down; whether it works with or without a hearing aid; where a person must stand for best reception (e.g., a loop induction system may only encircle part of the auditorium); and what you, as speaker, need to do to make the system work to its maximum potential. Do not depend on the hearing impaired visitor to know this information.

Written Material. Try to prepare written material to supplement verbal tour information for both hard of hearing and deaf visitors. By putting this information into a simple, easy-to-read format, you will serve both those who have lower language skills and those who want to skim the material. Written material should include:

1. a summary or outline of your tour (to be handed out before the tour begins)
2. a vocabulary list, including technical terms, proper names, and foreign words (also to be handed out at the start of the tour)
3. vocabulary cards for technical terms and proper names, to be shown at appropriate times during the tour
4. a reference list, including exhibit catalogs that explain more about the exhibitions.

When rewriting information, do not insult your audience. If you are writing for adults, use an appropriate style and try to:

- shorten the length of your sentences
- use a subject-verb-object sentence structure and the active, rather than passive, voice of verbs (e.g., "Bob ate pizza." Not, "The pizza was eaten by Bob.")
- avoid complex sentences with several clauses (e.g., write "A little girl lives next door. She ran out of the house when the fire started." Not, "The little girl, who lives next door, ran out of the house when the fire started.")
- choose vocabulary carefully and make sure any new or difficult words are defined
- avoid idioms, colloquialisms, and words with multiple meanings

- make sure that pronouns are kept close to their antecedents. Do not use the same pronoun for two different antecedents (e.g., write "It didn't seem right to take the ball." Not, "It didn't seem right to take it.")
- repeat a new or confusing idea several times in different ways. Try to write it differently each time.

(NOTE: Writing material for hearing impaired persons with lower language skills is a complex task requiring knowledge of manageable grammar at different levels of ability. For more information on this subject, see the text *Guidelines to Writing or Rewriting Materials for Deaf Students with Special Emphasis on Syntax* by Betty Rosenbloom.)

Captioned Audio-Visuals. If your tour includes slides, films, or videotapes, try to secure captioned versions of them. Films and slides can only be open captioned (with subtitles appearing on the screen). Videotapes may be open captioned or closed captioned (with subtitles appearing only when activated by a decoder connected to or inside the television). If you are using closed captions with a decoder, make sure you know where the decoder is located and how to use it.

Scripts of Audio-Visuals. If scripts of movies, films, slide shows, or cassette tours are available, be sure to offer them to hearing impaired visitors.

Practice Exercises

Exercise 1—Working With an Interpreter. Working in groups of three, you should practice touring a hearing impaired person with an interpreter. One docent should play the role of *docent*, one the *interpreter*, and one the *hearing impaired person*. If possible, a fourth docent could act as observer and critic, or the practice tour may be videotaped for critiquing. The best situation is, of course, to practice with a person who is deaf and with a real sign language or oral interpreter.

The group should practice the following:

- selecting well-lighted areas
- speaking clearly and at an appropriate pace
- positioning yourselves with respect to the object being discussed
- including appropriate tour objects and information
- editing tour information to allow more time for looking and asking questions
- facing the group and talking to the hearing impaired visitors
- following a commentary on an object with a pause for observing it
- using only nondistracting gestures that won't interfere with speechreading or sign reading
- allowing members of the group time to reposition themselves at a new exhibit

Exercise 2—Touring With a Hard of Hearing Person. Working in pairs, practice touring a hard of hearing person. One docent should play the role of *docent* and the other the *hard of hearing person*. Videotape your practice tours so you can better observe mouth movements, facial expressions, and gestures. The tape should be played back without sound so you can see how clearly the information would be conveyed to a hearing impaired person. If possible, a hard of hearing person should participate in the practice and critique of the tapes.

You can also practice speaking in front of mirrors, watching for clarity of mouth movements and comparing the readability of your normal versus slowed speech.

Emergency Procedures

In an emergency, follow procedures already established for your building or institution. Find out if your museum has a visual component to its emergency alarm system (e.g., flashing lights). If not, be aware that during an emergency, you might have to seek out and inform hearing impaired visitors of the situation. Here are some procedures to follow in addition to standard ones.

If a hearing impaired person is injured:

- Explain everything you are going to do before you do it. Make sure the hearing impaired person is included in all conversations. Imagine how you would feel if you were hurt and everyone was talking about you but you could not understand them.
- Use speech, speechreading, sign language, and/or message writing to communicate with the injured person.

If the building must be evacuated:

- Do not yell at a hearing impaired person from behind. He may not hear you or, if he can, be able to localize the sound.

- Do not grab a hearing impaired person from behind. Step in front of him or tap his arm to get his attention.
- Use facial expressions to show that there is an emergency. Talk, write, or sign to explain the situation. Be brief and clear.

Supplemental Information

Communication Modes

Oral/aural method. Individuals who use this method develop their speech and speechreading skills and learn to use their residual hearing for communication. They also use natural gestures and facial expressions.

Cued speech. This method uses manual cues to aid speech and speechreading. While a person talks, he uses eight hand shapes and four different hand locations (side of face, throat, chin, and mouth) to indicate different vowel and consonant sounds. Cueing specific sounds makes it easier for the person receiving the information to differentiate words that look the same when spoken, such as *mad*, *pad*, and *bad*.

Rochester Method. Using this method, the speaker fingerspells (using the manual alphabet) every word as he says it to aid his speech and speechreading.

Signing Exact English (SEE II). This sign language system uses signs that represent most aspects of English grammar such as words, verb tenses, prefixes, suffixes, possessives, and plurals. In addition, the system uses fingerspelling for proper names and other words that do not have signs. It is designed to aid language development and to be used simultaneously with speech (the speaker signs exactly what he says).

Signed English (Siglish). To convey his message, a speaker using this sign language system would use American Sign Language signs and fingerspelling but in English word order. The Signed English system also has sign markers to indicate verb tense, plurals, possessives, and gerunds. This system may or may not be used simultaneously with *voiced* speech (the speaker may instead mouth the words without sound for speechreading purposes).

Pidgin Sign. A speaker using this sign system would use American Sign Language signs and fingerspelling, in a combination structure of ASL and English, to convey his message. This system is at the mid-point in the grammatical continuum from the structure of Signed English to the structure of American Sign Language.

American Sign Language (ASL or Ameslan). American Sign Language is a manual language expressed through signs, fingerspelling, mime, formalized gestures, and facial expression. ASL is not a shorthand for English but a language by itself, grammatically different from English and from the sign languages of other countries. (Sign language is not universal.) ASL is solely a manual language and is used without speech; to use ASL and verbal English at the same time would mean signing in one language and speaking in another. In addition, there are formalized mouth movements that add meaning to certain signs and these would conflict with mouth movements for speech. A person who uses ASL is at the other end of the oral-manual spectrum from the person who uses the oral/aural method.

Working with Interpreters

Types of Interpreters. There are two main kinds of interpreters for hearing impaired people—sign language and oral interpreters. Usually, both types of interpreters are hearing people who have been trained to instantaneously interpret what the speaker says, but their mode of interpreting differs. A sign language interpreter translates the spoken word into sign language. An oral interpreter restates, without using voice, what the speaker is saying so the hearing impaired person can read his speech. The oral interpreter's location (with respect to his audience), facial characteristics, and knowledge of words that are not easily speechread all contribute to his "speechreadability." Both types of interpreters should position themselves near you but not in your way.

General Suggestions. The following are some general suggestions to help you work with an interpreter:

- Try to organize your tour around areas that are well lighted.
- Do not talk while you are walking; it is very difficult for the interpreter to work under these circumstances.
- Give the interpreter time to position himself in front of the group before you begin your talk.
- Do not walk in front of the interpreter while he is interpreting. Be animated in your talk, but try to avoid making large hand/arm movements and other

gestures which might distract the hearing impaired person from watching the interpreter.

- Talk at a moderate rate, using your normal speaking voice; some people may be using both their residual hearing and speechreading abilities to understand you.
- Speak clearly so that the interpreter can understand you. Do not turn your back to him or you will obscure your words. If the interpreter cannot hear you, no one will.
- Do not introduce the interpreter or mention him during your tour talk. The interpreter is there solely to communicate your presentation to the hearing impaired members of your audience.
- Talk directly to the hearing impaired person; look at *him*, not the interpreter. Never say, "ask him. . .," or "tell her. . .," to the interpreter.
- Do not lower the intellectual level of your talk; hearing impaired people are no more or less intelligent than people with normal hearing.
- Assume that the interpreter can keep up with you, but be aware of him as you talk. If he misses something you said or requests that a particular name be spelled, stop and give him the information before going on. If you are using slides or other visual aids, slow the pace of your talk slightly. This will give the hearing impaired audience members time to see both the interpreter and the visual aid.
- Spell difficult proper names, scientific terms, and foreign words.
- Try to avoid using vague terms such as *this*, *that*, and *it* when referring to details of exhibits. The hearing impaired person cannot look at the exhibit and watch the interpreter at the same time. If the person knows what you are referring to, he can find the detail when you are finished speaking.
- Be sure to give the hearing impaired members of the group some extra time to look at the exhibit when you are finished discussing it. They cannot observe the objects while watching the interpreter.
- Remember that the interpreter will repeat individual questions from the hearing impaired members of the audience if you do not understand sign language or the person's speech. (If the interpreter is using sign language, he will simultaneously sign the repeated question for the benefit of other hearing impaired audience members.) Look at the hearing impaired individual who asked the question; you are answering *that* person, not the interpreter.

Location During a Tour. The **sign language interpreter** should stand or sit as close to you as possible. This allows the hearing impaired visitor to look back and forth between you and the interpreter, and also ensures that the interpreter can clearly hear everything you say. During a movie, video presentation, or slide show, the optimal location for the interpreter is right alongside the screen with as much light as is necessary. If there is too much light spillage onto the screen, you should stand between the screen and the interpreter.

The positioning of an **oral interpreter** requires two considerations: the interpreter must be near the hearing impaired members of the audience; and you, the interpreter, and the audio-visual presentation (if any) must all be in their line of sight. Hearing impaired people should sit in the front rows, and the oral interpreter should sit in front of the stage, in line with you. This puts the interpreter at eye level with the audience, and you behind the interpreter. Be sure to consult both the interpreter and the hearing impaired individuals when determining exact locations.

Background. In both types of situations, the interpreter should stand or sit before a solid background that contrasts with his skin color. There should be no windows or other light source behind the interpreter.

Lighting. If you and the **sign language interpreter** are standing near each other, you can share the same lighting. A spotlight will be necessary, however, for interpreting a slide commentary or movie soundtrack in a darkened room. The light should be strong enough to clearly illuminate the interpreter's features. A straw-colored or cool gel will give appropriate lighting and not detract from the audio-visual presentation. Care should also be taken not to throw shadows on the interpreter's clothing and face or on the area behind the interpreter.

House lighting may be sufficient for effective **oral interpretation.** If the lighting level is too low, supplementary lighting may be necessary. If the room is darkened for an audio-visual presentation, then a spotlight must be used. A hearing impaired person who is speechreading depends on information conveyed by the interpreter's mouth (its shape, movement, and tongue location) and facial expression, so it is important to have sufficient, but soft, lighting on the interpreter's face. Diffused overhead lighting or a cool light coming from a source below and to the side of the interpreter is

most effective. Avoid small shadows on the face cast by the nose or other features.

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5

People with Visual Handicaps

Description of the Disability

People who are *visually handicapped* have a substantial vision loss that cannot be significantly corrected by eyeglasses or contact lenses. The degree of vision loss varies from individual to individual; however, people with visual handicaps can be divided into two major groups: those who are *visually impaired* and those who are *blind*. People with visual impairments have usable residual vision; people who are blind have little or no usable residual vision. According to the National Center for Health Statistics, there are approximately 14.3 million visually handicapped people in the United States; of this number, 125,000 are totally blind. About seventy percent of the visually handicapped population is sixty-five years of age or older.

Visual handicaps can result from diseases of the eye, eye infections, injury to the eye, medication, and hereditary disorders. Depending on the cause, an impairment can mean a loss of peripheral or central vision, hazy or blurred vision, tunnel vision, or a total loss of vision.

The type and severity of vision loss will affect how a person functions in a museum setting. For example, if a visually impaired person has decreased peripheral vision or tunnel vision, he may be able to see individual objects in a narrowly defined exhibit area but have difficulty traveling through a crowded room or exhibition hall. Mobility through unfamiliar areas may also be a problem for a person whose vision is impaired in the lower half of his visual field. When central vision is decreased (the most common visual impairment), an individual may be able to travel through the museum unassisted but find reading labels and viewing objects nearly impossible. A person with cataracts may have an overall haziness to his vision that becomes worse in glaring light; he may be able to travel (though hesitantly) through an evenly lighted museum but find viewing an object in a spotlighted glass case impossible. (For more information on the effects of different kinds of visual impairment, see the supplemental section "A Photographic Essay on Partial Sight," at the end of this chapter.)

These variations emphasize the importance of treating visually handicapped people as individuals. Always ask how to best assist *each* person.

Visual Impairment

Effects of the Disability

The visually impaired person is sometimes said to be partially sighted or to have low vision. The nearly 1.4 million people who have a severe vision loss cannot read regular-size newsprint even with corrective lenses. These individuals may use a variety of low vision aids, including magnifiers, closed-circuit television reading devices, and binoculars and monoculars. They may carry their aids with them to enhance their museum experiences.

You cannot assume that if one visually impaired

visitor can see an object clearly, another person with the same visual acuity will see it the same way. Some visually impaired persons have learned to use their residual vision more efficiently than others. Therefore, it is important to find out from each person what he *can* see in order to make his museum experience as beneficial as possible.

Education and Training

Visually impaired people generally receive the same type of education as sighted people. They are usually mainstreamed into regular classrooms where they use magnifiers, large print books, and "talking" books (records or cassette tapes of written material) to aid learning. By using dark graphite pencils or black felt tip pens, heavy black ink, specially lined paper, and large print typewriters, many students with very low vision can function at grade level.

Due to circumstantial or environmental factors, many persons with severe visual impairments function as if they were blind. Knowing this, professionals frequently provide them with orientation and mobility (O&M) training. Through orientation training, they learn to rely on their residual vision and other senses to acquire information about the environment; through mobility training, they learn how to move safely through the environment using travel aids (e.g., white canes, dog guides, sighted guides) and landmarks to guide them. (See the section on mobility aids for blind people in this chapter.)

Visually impaired people vary in their ability to learn and to use orientation and mobility techniques. Be observant. If a person seems to have difficulty getting around on his own, ask him what type of help he needs and offer your assistance.

Aids for Visually Impaired Individuals

Optical Aids

Eyeglasses and contact lenses. Millions of people in the United States wear eyeglasses or contact lenses; the majority of whom find that such prosthetics can correct their vision to 20/20 (standard vision). By most definitions, these people with totally or almost totally correctable vision are not described as visually impaired. For visually impaired persons, corrective lenses may improve such conditions as refractive errors, poor visual acuity, and the need for magnification, but for these people, some degree of impairment remains.

Telescopes. These are sometimes attached to eyeglass lenses to enable a person to see single objects more clearly. Although powerful, a telescope has limited use as a reading aid, since only one letter or word at a time can appear in the very restricted field of the lens.

Hand-held magnifiers. These are often used by stamp and coin collectors to see tiny dates and letters. They help some visually impaired people read regular print (found in most books) and smaller print (found in newspapers and telephone directories). Magnifiers are sometimes created specifically for an individual with special needs. If lighting is poor, however, magnifiers will be of little use; in some cases, illuminated magnifiers (providing both light and magnification) are used.

Binoculars and monoculars. These aids may help a visually impaired person distinguish small objects and details and are frequently used for reading signs, labels, and building numbers, and for seeing details in objects and photographs. A visually impaired visitor may use a binocular or monocular on a tour.

Blindness

Effects of the Disability

Blind individuals have no usable residual vision. Some blind people may have light perception; however, they cannot depend on vision to move about in the environment.

People who are congenitally visually handicapped begin to adjust to their impairment from their earliest years. They learn to depend on their other senses, particularly hearing, to obtain information they need. They do *not* have a "sixth sense" to compensate for their loss of vision; instead, they must learn to efficiently use the senses that they have. Congenitally visually impaired individuals learn to interpret the environment using hearing, touch, smell, and kinesthesia (e.g., recognizing doorways by feeling the moving air, the nearness of objects by the way the air moves around them and sound bounces off of them, and the difference between floor surfaces).

Individuals who lose their vision as teenagers or adults may have more difficulty adjusting, since they have learned to depend on their vision to function in

daily life. Adventitiously visually handicapped people need to overcome their negative attitudes about their vision loss and adjust to a new way of interpreting their environment. Their ability to use mobility techniques and to feel secure in their surroundings depends, in great part, on how long they have been blind and how well they have accepted their disability.

Education and Training

Many congenitally blind students acquire the skills they need for independent living and academic success while attending special schools and classes in the elementary grades. After that, the students are usually mainstreamed into classes with sighted children. In school, they acquire information mostly by listening and reading braille.

Blind persons may also receive special training at rehabilitation centers or through state and local rehabilitation programs. Classes in orientation and mobility (O&M) are provided through these programs. To achieve the greatest possible success, an O&M specialist individualizes the program to suit each person's needs and capabilities.

Aids for Blind Individuals

Mobility Aids

The cane. The cane is the most common aid for mobility. Designed to correspond to a person's height or length of stride, it is usually made of aluminium, fiberglass, or wood. For visibility, the cane is painted white and often covered with a reflecting material. The long cane may be rigid or collapsible (folding or telescoping). Most people use the collapsible kind because it fits easily into a purse or pocket when not in use.

To travel with a cane, the person holds it vertically in front of him at the center of his body, forearm angled downward. As he walks, he moves the cane from side to side, alternating it with the advancing foot. The cane indicates an area of safety for the next step and functions as a probe and bumper, giving back information about the environment. Many blind people learn to use a cane proficiently.

Instead of the traditional cane, some people now use special canes which bounce laser beams or sound waves off objects. These devices will beep, vibrate, or otherwise indicate that obstacles lie ahead. They vary in size, shape, and method of operation, but all basically serve the same purpose.

Dog guides. Also called Seeing Eye Dogs, these animals provide protection, a safe and fast means of travel, and even companionship for people who employ them as travel aids. Dog guides can be either male or female and are generally German shepherds, golden retrievers, or Labrador retrievers—breeds known for their intelligence, trainability, and stability.

A dog guide is rigorously trained before being matched with a person and must learn to respond appropriately to basic commands; react properly when confronting obstacles, curbs, pedestrians, traffic, and other animals; and protect the person from low branches and signs, heavy traffic, and crowded places. The dog must also learn "intelligent disobedience" so he can refuse a command that would endanger the person (e.g., an order to go ahead when there is an approaching car).

Through training, the blind person and the dog learn to work as a team. Even people who have some vision are taught to depend entirely on the dog, not their vision, for travel. Therefore, you should never distract a working dog guide by touching or talking to it; nor should you interrupt the dog's owner when he is correcting it. The visually handicapped person's life may depend upon the dog's attentiveness and obedience.

Sighted guides. The sighted guide provides a safe, fast means of travel through unfamiliar, crowded, or cluttered areas. Even if a blind or severely visually impaired person uses other mobility aids, he may occasionally require the help of a sighted guide. This is usually a family member, friend, or companion, but anyone may act as a sighted guide. (For information on how to be a sighted guide, see the supplementary section on sighted guide techniques at the end of this chapter.)

The choice of a mobility aid is a personal one based on an individual's needs, situation, lifestyle, age, and capabilities. For example, a cane gives back some information about the environment, but provides no protection from overhanging obstacles. The dog guide gives little information about the environment, but provides fast, safe travel. A sighted guide offers information and fast, safe travel, but limits personal independence. Individuals may use each of the three techniques at different times, in different situations.

Reading Aids

Audio tapes. Most blind people, even those who read braille, depend greatly on recorded materials. Books, exhibition catalogs, informational brochures, and ex-

hibit labels may be recorded for use by visually handicapped people.

Optacon (TM). This device, made by Telesensory Systems, Inc., converts the image of a printed letter into a vibrating tactile form that a blind person can feel with one finger. The Optacon produces exactly what is printed, thus enabling the blind individual to read directly from the printed page. To use the device, a blind person moves a miniature camera across a line of print with one hand, with the index finger of the other hand, he feels the enlarged letters on a tactile stimulator array. The Optacon is becoming popular because of its versatility; the device can be used to read nearly any type of print in any language.

Braille. This is a form of tactile communication in which a series of raised dots represent letters, words, and parts of words. About forty thousand Americans read and write braille. There are three grades or levels of braille, each progressively more complex; most brailled materials are produced in the middle level, grade two. Blind visitors may carry a slate and stylus (braille writing instruments) with them on a tour for taking short notes; for longer texts, they may use a braillewriter (a six-key braille typewriter).

Terminology

Visually handicapped The general term used to describe people who have a substantial loss of vision that cannot be significantly corrected.
Visually impaired The term used to describe people who have some usable residual vision. (These individuals are also referred to as being partially sighted or having low vision.)
Blind The term used to describe people who have no usable residual vision.

Remember that disabled persons are individuals and do not move, think, or act *en masse*. Therefore, they should be referred to as *disabled people*, not *the disabled*. People with visual impairments should be referred to as *visually impaired people*, not *the visually impaired*. Certain phrases used to describe visually impaired and blind persons evoke derision or inappropriate responses of pity or awe. Therefore, do not refer to a visually impaired or blind person as:

sightless
blind as a bat
in a world of darkness
suffering from . . .
a victim of . . .
afflicted by . . .
sentenced to a life of . . .
struck down
almost normal
superhuman
overcoming insurmountable odds
courageous

Adapting Your Tour

Evaluate the Accessibility of the Facility

Try to make the museum as accessible as possible to visually handicapped visitors. Look over the facilities before the tour and identify areas that might present problems. If you cannot correct these problems, consider making changes in your program such as planning an alternate route, selecting different exhibits, or preparing supplemental aids to compensate for information that the visually handicapped person will miss. Evaluate the following:

General Lighting. People with visual handicaps vary in their ability to see light. For some visually impaired people, lighting can dramatically affect their ability to read signs and labels, observe objects and details in photographs, and walk unassisted through exhibition areas. In general, certain types of lighting should be avoided. These include:

1. *very dim lighting*—often found in hallways, stairwells, basements, and back rows of auditoriums.
2. *very bright lighting*—often found in exhibition areas illuminated by spotlights; this can be a special problem when the area includes glass cases or other reflective surfaces.
3. *flickering lights*—sometimes caused by fluorescent ceiling lights that are poorly maintained or by light bulbs that are loose or defective.
4. *uneven lighting*—often found when a very dim area and a very bright area exist side by side (e.g., a brightly lighted artifact in a dark hallway). A visually impaired person may have difficulty moving from a brightly lighted area to a dimly lighted one. Some individuals need extra time for their eyes to adjust to a new level of light. If the change is too rapid, they may fail to see objects in their immediate path.
5. *natural light*—depending on the position of the sun, light coming through skylights or large bare windows can silhouette people or objects with backlighting or form "pools" that add to or conflict with artificial light.

Walkways. Visually impaired people may need guidance if the exhibition hall does not have a straight, uncluttered thoroughfare. Obstacles such as signs (especially those made of plexiglass) on the floor or hanging lower than eighty inches from the ceiling, walls that jut out unpredictably, throw rugs or runners with turned up edges, and objects on pedestals painted the same color as the floor or walls can be particularly hazardous—especially if the general lighting is poor.

Blind people may also need guidance if the walkways are cluttered with obstacles. A person depending on a cane to guide him around objects may fail to note low-hanging signs or unusually low doorways, overhanging water fountains and telephone booths, and objects on stem-like pedestals.

Stairways. Visually impaired people may have difficulty negotiating poorly lighted stairways or stairs without clear definition of height and depth. Marble stairs can be particularly dangerous; under certain conditions, they can merge visually to look like a steep ramp.

Blind people must be able to anticipate the location of the steps in a stairway. Therefore, they may have difficulty climbing stairs that are irregular in height and depth, or that lack handrails for guidance and support.

Acoustics. Blind and severely visually impaired people depend, to some extent, on sound to help them locate objects and people around them. However, high ceilings and large marble or granite rotundas can make sounds echo erratically and cause a visually handicapped person to temporarily lose his sense of direction. Offer guidance if you feel a person has become disoriented.

Exhibit Areas. Blind and visually impaired people will want to visit the museum's highlights—those objects and works of art that are most important to a museum's collection. Do not exclude important exhibits from the tour because of accessibility problems; instead, offer visitors models, photographs, and a good verbal description of the exhibit. (See the supplemental section on describing objects for visually handicapped visitors at the end of this chapter.)

Visually impaired people will benefit from exhibits that are well-lighted with no-glare exhibit cases. Avoid exhibits where objects are silhouetted by backlighting (e.g., a sculpture in front of a window) or are visually lost in a cluttered or similarly colored background (e.g., a blue lamp sitting in front of flowered or blue wallpaper). Exhibits designed for close viewing are good for visually impaired people. Let the visitor move as close as necessary (within the limits of museum policy).

Blind people will benefit most from touchable exhibits. If exhibits cannot be touched, supplement your regular presentation with models or a good verbal description. (See the supplemental section on describing objects for visually handicapped visitors at the end of this chapter.)

Introduce Yourself

If you know ahead of time that a visually handicapped person is coming on your tour, try to meet him at the entrance of the building or at another easily located landmark. Many visually handicapped people cannot recognize uniforms or read identification badges, so you should initiate contact. Touch the person's arm lightly to get his attention, introduce yourself, state your role in the museum, and ask if you may be of assistance. Always talk directly to the visually handicapped person; never talk to him through someone else. Use his name to indicate you are speaking to him and let him know when you are approaching or leaving.

Start with a Verbal Orientation

Find out how familiar the visually handicapped visitor is with the layout of the museum. If he is a first-time visitor, he may have difficulty orienting himself. Describe the general layout of the building using a single reference point. For example, "The exhibition area is in the shape of a cross with a fountain in the center. We are standing at the bottom of the cross." Then discuss the exhibits you plan to visit and their location in relation to the reference point. Ask how much introductory information you should provide and encourage people to ask questions and make comments.

Offer Your Assistance

Ask the visually handicapped visitor if he needs assistance getting from one exhibit to the next during the tour. Don't be offended if he declines your help. The ability to get around varies widely among visually handicapped persons and often depends on the situation. If your offer to be a sighted guide is accepted, allow the person to take your arm. Hold your arm close to your body and walk slightly ahead of the person you are guiding. (For more information on sighted guide techniques, see the supplemental section at the end of this chapter.)

Speak Clearly and with Enthusiasm

Remember that visually handicapped people often depend on a speaker's tone of voice and inflection for information they might otherwise get from facial expression and gesture. Make your voice convey interest and enthusiasm for the information you present. Use words like *look* and *see*—they are part of a visually handicapped person's vocabulary, too.

Choose an Uncluttered Route

Check walkways for obstacles and abrupt turns. Make sure visitors can move easily from one exhibit to the next.

Include Touchables in Your Tour

- Find out beforehand which objects in an exhibit a visually handicapped visitor is allowed to touch, and whether or not sighted visitors are also allowed to touch them. If not, explain this to the visually handicapped individual and let him decide if he wants to be singled out to touch artifacts.
- If objects can be touched, encourage the visually handicapped person to feel or hold them. (Many people are afraid to touch things in a museum, even if given permission.)
- When describing touchable objects, offer information that is supplementary, not redundant, to what the person sees tactually. Encourage questions to ensure that you are offering appropriate detail.
- If objects in an exhibit cannot be touched, try to provide touchable models or objects similar in use or appearance. Tell the visually handicapped person that the touchable object is a substitute and explain how it is like or different from the original. Remember to show the objects to everyone in the group.
- Do not plan your entire tour around touchables. Maintain continuity to keep the tour flowing smoothly.

Allow for Individual Differences

The way visually impaired people see, the type of description they want, and the amount and kind of assistance they need will vary. Be flexible when planning your tour. If people in your group have different vision levels, make the tour appropriate for the lowest level but encourage everyone to participate; sighted visitors or those with moderate vision loss can provide details and descriptions to people who are more severely disabled.

Use Supplemental Aids

Printed material. All handouts should be as readable as possible. The ability of visually impaired people to read maps, brochures, and other material related to your tour will vary with the degree of disability. Lighting, type size and typeface, amount of text, color contrast, and paper quality affect the readability of printed matter. Large print (at least ¼-inch high) that is dark and clear on ivory-colored, matte-finished paper works well. There should be plenty of space between lines of text.

Recorded material. Those visually impaired and blind individuals who cannot read print or braille will find recorded material especially helpful. Contact the National Library Service for the Blind and Physically Handicapped for information about organizations that will record your material.

Exhibition labels. These can be made more accessible to visually handicapped visitors if also supplied in large print, braille, or recorded versions. Braille labels might be on the regular exhibition label itself or stored separately; either way, they should be readily available to accommodate a self-guided tour or to supplement a docent-led tour. Large print or recorded versions of labels may be borrowed by individuals and used for self-guided tours or as supplements to information given by the docent.

Magnifiers. These devices are particularly useful when detail is important. They are most useful when held close to the object being examined.

Raised-line drawings. These are used to represent objects that cannot be touched or that are too large to touch and experience as a whole. The drawings are made by a thermoform process (during which plastic is melted over a slightly raised image to duplicate that image). There are two basic forms of raised-line drawings: a single-line drawing showing only the outline of the object (as in tactile maps) and a three-dimensional drawing reproducing the model in detail.

Photographs. Through photography, many visually impaired people can experience objects that are very large, very small, very detailed, poorly lighted, or difficult to see within an exhibition. Photographs can provide small images of large objects or enlarged images

of small objects. Through photographs, many visually impaired people can see details they might otherwise miss. Choose photos for clarity of detail and high tonal contrast. If you photograph objects expressly for this purpose, place them in front of solid, high-contrast backgrounds (e.g., light objects against dark backgrounds). Laminate the pictures with a matte finish and assemble them in a ring binder or sturdy folder so they can be easily seen and handled. Encourage visitors to compare what they see in the photograph to what they can see of the actual object. If there are sighted people on the tour, share the photographs with everyone; hand them first to the visually impaired person and ask him to pass them on. That way, the whole group will enjoy a closer look at the objects and the visually impaired person will not feel singled out.

Make Up an "Additional Readings" List

Contact the National Library Service for the Blind and Physically Handicapped to obtain titles and identification numbers of books on cassettes or records and of books in large print or braille that relate to your tour or the museum in general. This list of books can be made available to visually handicapped visitors for follow-up information.

Practice Exercises

The most effective way to practice these exercises is to work through them with an individual who is visually handicapped. If this is not possible, you or another docent may act the role of a visually handicapped individual.

Exercise 1—Sighted Guide Techniques. Work in pairs for this exercise, with one docent acting as the *sighted guide* and the other as the *visually handicapped visitor*. The docent acting as visitor should keep his eyes closed or blindfolded throughout the exercise. (This is *not* to simulate the disability but rather to help the guide take total responsibility for guiding.) A path should be designated ahead of time that allows practice in guiding an individual through narrow places and cluttered areas, onto escalators or into elevators, up and down stairs, and into a seat. When you reach the end of the path, reverse roles and walk back to the starting point.

Exercise 2—Visual Description Techniques. Variation 1. Work in groups for this exercise. Each docent should be assigned a single object to study and describe. (All assignments must be kept secret.) Each docent should then go to his assigned object and develop a good visual description that not only names the object but details its color, shape, texture, and size. When the group reassembles, each docent should give a visual description of his object without naming it or giving its location. The group should try to identify the object and to critique the description.

Variation 2. Working in pairs, one docent should act as *docent* and the other as the *visually handicapped visitor*. The docent should guide the visitor (who is either blindfolded or keeps his eyes closed) into a room or gallery and to an object. The docent should then describe the object carefully and answer the visitor's questions. Afterward, the visitor should open his eyes and look at the object to judge the effectiveness of the description. Change roles and repeat the exercise. This activity can also be done using touchable objects.

Variation 3. Working in groups of four, docents should take the following roles: one *docent*, one *visually handicapped visitor*, and two *sighted visitors*. The person acting as docent should practice giving enough description to interest and inform the visually handicapped visitor but not enough to bore the sighted visitors; involving the sighted visitors in sharing information with the visually handicapped visitor; circulating touchables and/or photographs; and encouraging the visually handicapped person (but not the sighted visitors) to touch objects within the tour context. Continue practicing this exercise until everyone has had a chance to act the role of docent.

Emergency Procedures

In an emergency, follow procedures already established for your building or institution. However, a visually handicapped person may require additional attention in a crisis. Here are some procedures to follow in addition to standard ones.

If a visually handicapped person is injured:

- Make sure that he is aware of his surroundings and explain all procedures before administering first aid. Remember that he cannot see where you are taking him or what you are doing. Avoid startling or scaring him; explain first and then act.
- Find out what to do with his dog guide if he must be taken to a hospital by ambulance. If he is conscious, ask if there is someone you could call who would

take the dog and get instructions on how to care for the dog until someone can pick it up. If he is unable to give you this information, call a local agency for blind persons. Ask for the name of a kennel that would temporarily take care of the dog.

If the building must be evacuated:

- Seek out the visually impaired person and explain the emergency.
- Assist the person in locating the stairway and/or exits.
- Stay with the person until he is safely out of the building. Do not leave him outside without telling him you are doing so.

Supplemental Information

Sighted Guide Techniques

A sighted guide assists a visually handicapped person to move safely and efficiently through different environments under varying conditions. A guide must react properly when confronted by obstacles and dangerous situations and must provide information about the environment through verbal description and body movement.

The following are some basic techniques used by sighted guides. However, some visually handicapped persons, particularly those who have recently lost their vision, may not be familiar with these methods. Talk with the person you are guiding to find a system that is comfortable for both of you.

1. Let the blind person know who you are and when you are approaching or leaving him.

2. Ask the visually handicapped person if he would like assistance, and if so, what type of assistance.

3. If your services as a sighted guide are accepted, touch the person's hand or arm with the back of your hand—this will let him know where you are. Allow the person to take your arm above the elbow. (The person who needs more support may hold onto your forearm.) Then hold your arm close to your body for additional support. Walk at your normal pace, if that is comfortable for the person you are guiding. Be sure to stay slightly ahead of him. Remember that visually handicapped people are not fragile. Talk to the person you are guiding—and relax.

4. When moving through a crowded or narrow area, place your guiding arm behind you, forearm across your lower back. The person should move directly behind you, shifting his hand to hold your forearm.

5. Be aware of objects that might present problems for visually handicapped persons: wires or ropes on the floor, edges of carpets, low-hanging lamps or tree branches, low doorways, and exhibit cases that stick out. Be sure that your guidance helps the person avoid these obstacles.

6. For visually impaired persons, objects that blend into the background, floors and walls of the same color, objects in the center of walkways, glass, and too much or too little light present considerable problems. A visually impaired person usually will not require assistance to get around; however, he may request or accept aid when moving through cluttered areas.

7. Tell the person something about his surroundings as you go along if he is interested. Information about the type of architecture, the style of decoration, the building materials used, and some of the objects being passed will help orient him to the museum. Ask him how much information he wants to receive.

8. Your natural body movements will convey to the person that you are stopping, turning, or going up or down an incline. The person, however, may feel more comfortable if you also tell him where you are going next.

9. Pause before going up or down curbs and single or double stairs. Tell the person that the elevated or lowered area is coming and whether it is a step up or down.

10. Tell the person whether you are at the top or bottom of a flight of stairs. The person may feel more secure using the handrail to go up or down the stairs in addition to holding your arm. If so, guide him to the rail and describe its location. Take the first step, pause, then proceed up or down the stairs.

If you need to go up and down stairs in single file because the stairs are crowded, precede the visually handicapped person. Tell him you're going ahead and guide his hand to the rail on the right (or left). When you get to the top, tell the person that you're at the top, then move ahead to allow room for him to step safely onto the landing, at the same time extending your arm back to where the railing ends. This way, he can immediately find your arm and reorient himself to taking your arm on the flat surface again. It can also help to just say to the person, "You have one more step before the landing."

11. Always tell the person when you are about to use an elevator, escalator, turnstile, or revolving door. Pause before using any of them.

Elevators. Enter the elevator and turn to face front. The person will turn following your body movements. Describe the location of the control buttons (e.g., to the right of the door, three feet from the ground).
Escalators. Some blind people prefer not to use escalators unless it is absolutely necessary. (This is particularly true of people who have dog guides.) If you must use one, however, place the person's hand on the moving rail before getting on in order to give the person support. Step onto the escalator together. Tell him when you are coming to the top or bottom stair and when you are stepping off the escalator.
Turnstiles. Before going through a turnstile, place your guiding arm behind you as you do for narrow places (see number 4) to cue him to follow you single file. Precede him through. Then place his hand on the turnstile arm and let him go through. Allow him to take your arm again on the other side.
Revolving doors. Try to avoid revolving doors. If it is necessary to use one, enter together and make sure that there are no obstacles on the other side of the door. Allow him to precede you out of the doorway.

12. Tell the person if there is a door and which way it opens (toward you or away from you). When the door opens on your side, you should open the door and allow him to hold it while you both pass through.

13. When guiding a blind person to a seat, place his hand on the back or arm of the chair. Allow him to seat himself.

14. The blind or visually impaired person will know how you can best assist him. Occasionally ask if the assistance you are providing is appropriate and helpful. Often the person will tell you how you are doing as you go along. Be aware of cues the person gives to help you personalize the experience for him (e.g., preferred walking speed, amount of orientation information desired, style of description). Most often, common sense and reflex actions will guide you both.

Methods of Description

General Suggestions

1. Ask the visually handicapped visitor how much he can see of the painting, object, or room and how much description you should give to enhance his appreciation of it. To help him give you this information, you might point out specific aspects of the painting, object, or room and ask if he recognizes them. For example, "On the right side of the painting is a woman in a blue dress sitting by a fountain. Can you see her clearly?"

2. Give a description of the overall exhibit, room, or display; work from general facts to specific details. Locate the objects you discuss within the context of the exhibit, room, or display.

3. For a large object, pace out together the object's length and width. Describe the height of the object in comparison to the person's height or to the object's own width.

4. Relate descriptions of the object to familiar things. For example, "It is about as large as your hand." Or, "It is shaped like a canoe, but made of wood."

5. Describe things using language that the general public will understand. The person's questions will indicate if more detailed or technical information is desired.

6. You should occasionally ask if you are giving the right amount of description. Be sensitive to how much the person or group members want to know.

7. If possible, as you move between exhibits, describe what you are passing. For example, if you pass another exhibit area, mention this with a one-sentence description of the collection.

8. A person may ask for exhaustive description of an object or work of art. Understand that the visually handicapped person may need this information to better appreciate the object or work of art that you describe.

Paintings

1. Present the historical background, including the artist's name; the painting's title; the period, school, or style of the painting; and any other information that you would provide about it for the general public.

2. Give a visual description of the painting, working from the general theme to the specific details: describe the painting's size, setting, composition, subject or theme, major color scheme, texture, characters, and most interesting details.

Sculpture

1. For all sculpture, give a historical background. Include the sculptor's name and the sculpture's title; provide the style, period, date, and other details you would give to a general audience.

2. For untouchable sculpture, give a visual description of the work: describe the sculpture's size, material, texture, color, facial and physical characteristics, and expression.

3. For touchable objects, be sensitive to what the person touching the sculpture wants to know. Encour-

age him to ask questions and make comments. Suggest that he use both hands, not just the fingertips, to explore the work. Try not to tell him what he can already understand by touching. For example, "This is a smooth, round surface." Rather, offer information that will help him interpret the work. For example, "This is an abstract representation of a woman. The metal it is made from is painted red." Allow more time when using touchables—it takes longer to look at sculpture through touching.

Historical Objects

1. Begin with the object's significance in the context of the collection. Include such information as why the object was made, when it was made, and what it is made of.

2. Describe how the object looks. If you have objects that can be touched or models of them, present them in much the same way as you would present touchable sculpture.

Scientific Objects

1. Describe scientific objects basically the same way that you describe historical objects. Discuss who invented the object, why it was important, what led to the object's development, and how it works. To help the visitor, compare the object to familiar things, defining any technical terms, as necessary. Explain the object's significance in the collection.

Historical Rooms

1. Give a historical background for the room: the period of the furniture, the type of room and who used it, and important events that took place there. Give the same information that you would present to general audiences.

2. Present a visual description of the room, including its size, lighting, color, and furnishings. Mention unusual aspects of the room: windows, draperies, rugs, fireplaces, paintings, and other wall hangings.

3. Describe two or three significant items in the room. Choose unusual items that might be of particular interest to the visitors or that have an interesting history, a unique appearance, or a character typical of the period or type of house. Describe a historical object by giving its size, color, shape, and material; then mention where the object is located in the room, why you selected this object to describe, and how and by whom it was used.

Reference Notes

p. 33 APPROXIMATELY 14.3 MILLION: National Center for Health Statistics, *Current Estimates From the National Health Survey: United States, 1983* (Washington, D.C.: U.S. Department of Health and Human Services, June 1986), p. 92.

p. 33 ABOUT SEVENTY PERCENT: D. Grayson, *Facts About Blindness and Visual Impairment* (New York: American Foundation for the Blind, Inc., 1983), p. 2.

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p. 35 THE CANE: J. A. Murphy, *How Does a Blind Person Get Around?* (New York: American Foundation for the Blind, Inc., 1978), pp. 9–10.

p. 36 ABOUT FORTY THOUSAND AMERICANS: An undocumented estimate offered in telephone conversations with staff members of both the American Council of the Blind and the National Library Service for the Blind and Physically Handicapped.

p. 38 PHOTOGRAPHS: G. Covington, "Photography Aids Visually Impaired Museum Visitors," *Roundtable Reports: The Journal of Museum Education*, vol. 6, pp. 6–7.

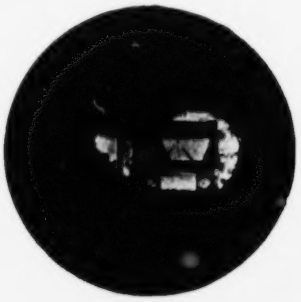
A Photographic Essay on Partial Sight

Photographs by D'Arlene Studio
Eleanor E. Faye, M.D., Ophthalmological Consultant
Pictures representing the eye diseases are done as if the camera were the right eye.

The Field of Vision
(peripheral vision) with both eyes is 180 degrees.

Normal Vision
A person with normal or 20/20 vision sees this street scene.

Macular Degeneration
The most prevalent eye disease. The picture shows the area of decreased central vision called a *central scotoma*. The peripheral or traveling vision remains unaffected.



Glaucoma
Advanced glaucoma involves loss of peripheral vision but the individual still retains most of his central vision. Early detection and cooperation with good medical care can prevent this drastic loss of vision.

Cataract
Diminished acuity from an opacity of the lens. The field of vision is unaffected. There is no scotoma, but the person has an overall haziness of the view, particularly in glaring light conditions.

Corneal Pathology
When the cells of the cornea are damaged or injured, the image becomes distorted or clouded so that clear detail is no longer discernible. The *field of vision* is normal.

Hemianopia
A defect in the optic pathways between the eye and brain. Vision is lost in half of a field. The most common defect occurs in corresponding halves of the right field of vision which causes reading impairment, right homonymous hemianopia. It can also occur on both left halves of the field of vision. When the defect is an inferior hemianopia, there may be interference with traveling and reading. When the visual defect is in the upper half, it is a superior hemianopia.

Retinitis Pigmentosa
Commonly called "tunnel vision." Only a small area of central vision remains in these cases and traveling is difficult without side vision.

Retinal Detachment
Shown here in the active stage. There are many causes for detachment, but the hole or tear allows fluid to lift the retina from its normal position. This elevated retina causes a field or vision defect, seen as a dark shadow in the peripheral field. It may be above, or below.

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6

People with Mobility Impairments

Itzhak Perlman is widely acclaimed as one of the finest violinists in the world. He travels throughout the United States, Europe, and Asia each year giving virtuoso performances and playing with the world's major orchestras. Obviously, a man of such talent and worldliness can speak for himself—yet many assume he cannot. As a child, Perlman had polio; he now uses leg braces, crutches, and occasionally a wheelchair as mobility aids. The polio affected his ability to walk; it did not affect his ability to talk. But he told a *Washington Post* reporter, "When you are in a wheelchair, people don't talk to you. . . . I will be traveling, with someone pushing my wheelchair, and when we come to the passport station the officer will ask 'Where is his passport?' I always make sure that I have my passport with me, and I look up at him [and] say, 'I have my passport.' I make him talk to me."

Many nondisabled people do not understand the effects of mobility impairments and, as a result, treat individuals with this disability inappropriately. People who are mobility impaired have difficulty using, or cannot use, one or more of their extremities (i.e., arms, hands, legs, or feet) or lack the strength to walk, grasp, or lift objects. Whatever the cause of the disability—the loss of an extremity; spinal cord injury or disease; neurological impairment; or cardiovascular, respiratory, and other illnesses—mobility impaired persons are often the most visible of disabled persons, mainly because of their assistive devices: they may use wheelchairs, crutches, canes, or artificial limbs to aid them in their daily movements.

Effects of the Disability

The term "mobility impairment" is a very broad umbrella that covers disabilities ranging from a missing hand to quadraplegia. Although it is not necessary to be able to identify any specific condition, you will need to recognize the variety under this term. This chapter describes nine major disabling conditions, but you will be generalizing from these—such as how they affect an individual on tour—to other mobility impairments.

Arthritis

The word *arthritis* comes from the Greek terms *arthron* (joint), and *-itis* (inflammation). The condition has probably been around as long as vertebrate animals have roamed the earth; it appears to have affected dinosaurs and flying reptiles as well as the ancient Egyptian ruler, Rameses II.

Approximately thirty-one million Americans have arthritis, and about three out of every hundred of those people need to use wheelchairs. Many others have difficulty climbing stairs, walking long distances, reaching for objects, and doing fine work like sewing and woodcarving. In addition to affecting the joints, some kinds of arthritis may also damage organs such as the spleen, heart, and liver.

Arthritis is really an umbrella term covering eighty to a hundred different conditions including osteoarthritis, rheumatoid arthritis, juvenile rheumatoid arthritis, and bursitis. The causes of most forms are unknown.

Osteoarthritis ("wear-and-tear" arthritis) is the most common form of arthritis, mainly affecting middle-aged and elderly persons. It results in stiff joints but causes little inflammation or permanent change in joint shape. Stiffness is most likely to occur upon rising in the morning or after being seated for an extended period of time. Pain can range from mild to severe, limiting motion and fine motor coordination accordingly.

Rheumatoid Arthritis is a form of the disease that is usually progressive causing inflammation of the joints. Symptoms include swelling, pain, stiffness, and some-

times, permanent change in the shape of the joints; often there is accompanying fatigue and loss of appetite and weight. Rheumatoid arthritis usually begins in people between the ages of twenty and forty; it may progress for a while and then end, leaving the individual without symptoms, or it may continue until it seriously damages many joints, leaving the person severely disabled.

Juvenile Rheumatoid Arthritis follows the same pattern as (adult) rheumatoid arthritis and can leave a child permanently and severely disabled. It begins to affect children before the age of eighteen and may last only two or three years, or it may continue through adulthood. Juvenile rheumatoid arthritis is very prevalent in the United States today; it now affects greater numbers of children than polio did during its most severe epidemic.

Bursitis occurs when the bursa—a saclike structure that serves as a cushion for muscle or tendon movement over a joint—becomes inflammed. Bursitis often occurs in the hip, shoulder, or elbow joints and can be very painful. Large and small movements alike are affected, with degrees of limitation dictated by the severity of pain. Bursitis may recur in the same area or develop in new joints.

Stroke

This most common disorder of the nervous system is a sudden impairment of cerebral circulation in one or more blood vessels supplying the brain. It may be caused by a blood clot blocking brain arteries or a cerebral hemorrhage of a blood vessel and can result in serious damage to brain tissue. Effects of a stroke can be rehabilitated but the process is long and slow and some residual disability may remain.

A stroke generally affects only one side of the body: if the right side of the brain is damaged, the left side of the body may be weak or paralyzed; if the left side of the brain is damaged, control over the right side of the body is affected. Some voluntary muscle control over arms and legs may be lost; the limbs may become passive or rigid or there may be involuntary muscle contractions. Additional effects of a stroke might include:

- having difficulty producing or understanding speech and language
- having visual perceptual problems (affecting balance and distance judgment)
- losing the sense of touch or a having a hypersensitivity to the sense of touch
- losing the ability to determine what a body part is doing without looking at it
- experiencing memory disorders (particularly short-term memory)
- having a short attention span and distractibility

Missing Extremities

The absence of any extremity, from part of one finger to all four limbs, may be congenital (existing prior to birth) or adventitious (resulting from an accident or disease). Many individuals who have missing extremities are fitted with prostheses and/or learn how to use the remaining parts of their limbs.

Multiple Sclerosis

Although multiple sclerosis was identified in 1835, the cause and cure have not yet been discovered. According to the National Institute of Neurological and Communicative Disorders and Stroke, approximately 500,000 Americans have multiple sclerosis or multiple sclerosis-related conditions.

MS, as it is commonly called, frequently begins when people are between the ages of thirty and forty. A disease of the brain and spinal cord, it randomly destroys parts of the covering of the nerve fibers of the central nervous system, which results in interruptions of the messages being sent between the brain and the rest of the body. MS affects particularly those messages that control movement, sight, and sensation.

The way multiple sclerosis affects people varies from person to person. One person may have one acute attack and never have another; a second person may have several attacks followed by month- or year-long periods of remission, the most common pattern that may or may not lead to permanent paralysis; a third person may have continuous attacks and steadily become more and more disabled until he cannot function independently.

Symptoms of MS include blurred vision or temporary blindness, weakness or paralysis in a lower limb, loss of feeling in an arm or leg, and tremors in an arm or leg. Each new attack of MS increases the chance of permanent paralysis.

Muscular Dystrophy

Muscular dystrophy is a group of degenerative muscular diseases that usually have a genetic cause and no cure. They begin to affect the individual in childhood or adolescence, usually after muscles have begun developing normally.

There are several types of muscular dystrophy; the Duchenne type (also called DMD) is the most common, and begins in children between two and six years of age. At first, the child has trouble rising from a seated or squatting position, climbing up steps, and raising his hands above his head. He walks with what has been described as a waddle. As the disease progresses, the child loses more and more muscle power and uses first braces, then crutches, and finally a wheelchair to aid his movement. Though muscular dystrophy does progressively limit the child's motor skills, it does not affect his intelligence.

Spina Bifida

Spina bifida is a congenital disability in which the spine is not fully formed during prenatal development causing openings that expose one or more of the vertebrae. The nerve tissue may then form a sac that protrudes from the body. Surgery can be performed to repair and hide the sac, but it cannot reverse the nerve damage that blocks or slows messages between the brain and the rest of the body. The resulting disability may range in severity from muscle weakness with reduced skin sensation to paralysis of the lower body and total lack of sensation.

This disability is sometimes accompanied by hydrocephalus, a condition in which there is too much spinal fluid in the brain. Because the fluid pressure can cause brain damage, children with both spina bifida and hydrocephalus may also have mental retardation; epilepsy; hearing, visual, and speech problems; and learning disabilities.

Poliomyelitis

Also known as polio or infantile paralysis, poliomyelitis is an acute viral infection of the spinal cord and/or brain stem. Poliomyelitis epidemics occurred in the United States from the turn of the century until 1955, when the Sabin and Salk vaccines were developed.

Depending on the location and severity of the infection, resulting disabilities may include weakness or paralysis of the lower limbs and difficulty in breathing, swallowing, and speaking.

Spinal Cord Injury

According to the Paralyzed Veterans of America, an estimated 250,000 to 400,000 Americans have spinal cord injuries, and every year another 10,000 injure their spinal cords in accidents. The majority of these people are men under the age of thirty. As is true with other spinal cord-related mobility impairments, the severity and type of disability depends on the location of the damage—the higher up on the spinal cord that the injury occurs, the more comprehensive the disability. For example, if the injury occurs in the neck area, then the entire spinal cord below is affected and paralysis in both the arms and legs (quadraplegia) can result. However, if the injury occurs in the chest area or below, only the lower body will be affected (paraplegia).

Persons with spinal cord injuries may have either a total or partial loss of sensation and muscle control. They may also have muscle spasms and lack control over other bodily functions.

Cerebral Palsy

Most people who have cerebral palsy are mobility impaired to some degree. However, due to the wide range of other impairments also affecting people with cerebral palsy, an entire chapter (chapter seven) of this manual is devoted to the disability.

It is important to remember that the estimated 12.5 million people who annually sustain fractures or sprains necessitating casts and crutches are temporarily mobility impaired. The same considerations must be made for them as for people with permanent mobility impairments.

Education and Training

Provided they have no accompanying disabilities, most children with mobility impairments are mainstreamed full-time in regular classrooms throughout their formal education.

Individuals who have adventitious mobility impairments may receive physical therapy and training in the use of artificial limbs or other assistive devices. They may also receive instruction in self-care and other daily living skills.

Mobility Aids

Braces. Leg and foot braces are used for increased mobility, protection from injury, and prevention of disabling bone formations.

Special shoes. People with foot disabilities such as bursitis and arthritis may use special shoes as mobility aids. Individuals who have one limb that is shorter than

the other may also use special shoes; these shoes may have built-up soles to compensate for the difference in limb length.

Prostheses. Limb prosthetics exist for both upper and lower extremities. They can be fitted for people with missing extremities both above and below the knee and the elbow. The prostheses are frequently made of lightweight plastic laminates and are held in place by suction, straps, or harnesses.

Canes and walking sticks. These aids are the most frequently used by mobility impaired people. Canes usually have rubber tips for gripping and may have three to four prongs at the bottom end for better stability. People may use one or two canes for support.

Crutches. People use crutches to help support their weight while walking. Crutches may be either the traditional H-framed or the Canadian forearm style, both made of either wood or aluminium.

Walking frames. Walkers are metal frameworks that help people support their weight and aid their balance. They are more stable than either canes or crutches, but take up much more space. The following are variations of the walking frame.

- Reciprocating walkers have corners that are jointed to allow the angles to "walk" with the mobility impaired person.
- A walker with wheels maneuvers easily for a person not strong enough to lift it.
- A hemi-walker can be controlled with only one hand.

Wheelchairs. Wheelchairs are now available in several forms, each with a large number of options.

- A standard adult wheelchair measures 24 to 26½ inches in width and weighs 25 to 50 pounds. It is manually operated by gripping and pushing the rims on the two large drive wheels.
- A motorized wheelchair is the same size as the standard wheelchair, but weighs between seventy-five and eighty pounds. It is powered by a battery pack, located on the back of the chair, that runs continuously for six to eight hours before it needs recharging. The controls can be operated by the pressure of the person's left or right hand, finger, chin, or breath. In an emergency, a motorized chair can be manually operated.
- A three-wheeled motorized wheelchair resembles a scooter. Its wheels (one wheel in front and two in back) are connected by a platform. It runs on rechargeable batteries that give it a range of up to fourteen miles a day. Attached to the platform is a swivel seat (adjustable for height) with backrest and arms and a central hand control for steering and power. Three-wheeled vehicles are narrower though heavier than standard motorized wheelchairs; they vary in width from eighteen to twenty-six inches and weigh about one hundred pounds.

Terminology

Mobility Impaired This term is used to describe an individual who has difficulty using, or who cannot use, one or more of his extremities to walk or to hold or pick up an object.

Remember that disabled people are individuals and do not move, think, or act *en masse*. Therefore, they should be referred to as *disabled people*, not *the disabled*. People with mobility impairments should be referred to as *mobility impaired people*, not *the mobility impaired*. The mobility impaired person is neither the disability nor the assistive device; therefore, do not refer to him as:

a cripple
an MD (muscular dystrophy)
a spina bifida
a CP (cerebral palsy)
cerebral palsied
an arthritic
a patient
afflicted with. . .
a victim of. . .
suffering from. . .
crippled or lame

The mobility impaired person in a wheelchair is a "wheelchair user," not "a wheelchair." He is also not "confined" or "bound" to a wheelchair. A battery-powered wheelchair is called a "motorized wheelchair" and not an "electric chair."

Adapting Your Tour

Evaluate the Accessibility of the Facility

Make your building as accessible as possible to mobility impaired people. Even if they are not participating in your tour, you should always know the location of elevators, wheelchair lifts, and ramps; emergency and

other exits; audio-visual equipment and programs; and artifacts or models that could be brought to an individual who is unable to reach an exhibit. Provide accessibility for all kinds of aids since mobility impaired people use a variety of assistive devices including wheelchairs, canes, crutches, and artificial limbs; be sure to evaluate accessibility for all types of aids. The following may present particular problems for the mobility impaired individual:

Stairs and Curbs. A person walking with an assistive device may have trouble with stairs and curbs. Stairs should be smooth but not slippery and should have edges without lips. At least one side railing should run the full length of the staircase, extending twelve inches beyond the top and bottom stairs. Elevators may still be the preferred means of moving from level to level; however, if there are no elevators or if stairs are more convenient, the individual should be given the option to climb.

For an individual in a wheelchair, stairs present the greatest problem; an elevator or wheelchair lift may be essential. If these are not available, program changes (such as slide or video presentations of upper level exhibits or moving a second-story activity to the first floor) will be necessary. Outside, curb cuts will aid independent travel; if curb cuts are not provided, the individual may need special assistance. (*Always* ask the wheelchair user how to safely aid him in mounting a curb.)

Floors, Carpets, and Ramps. For an individual walking with an assistive device, slippery surfaces (such as a highly polished floor) are extremely hazardous. This individual may need a wheelchair to proceed safely through the area. Steep grades and rough, uneven, or differing surfaces (e.g., a rug next to wood planking next to tile) may also be dangerous; the person may need special assistance if these areas cannot be avoided.

For an individual in a manually operated wheelchair, deep-pile carpeting, rough or uneven surfaces, and steep cross-slopes (a surface's incline from side to side), inclines, or ramps may make independent travel difficult. If these conditions exist, the person may need someone to assist him through the area or to help him find an alternate route.

Narrow Spaces. An individual in a wheelchair needs a certain amount of space to maneuver through and turn around in. For example, doorways must be at least thirty-two inches wide (preferably thirty-six inches wide) and a turning space must have a sixty-inch diameter to accommodate a wheelchair user. If doorways are not wide enough, or if exhibit space is too limited or cluttered to accommodate someone in a wheelchair, make program changes.

Labels and Signs. A person in a wheelchair has a lower line of vision than a person who is standing. Therefore, signs and labels positioned for the standing viewer may be too high for him to read. If labels are a problem, provide label texts (the same large-print labels that are used with visually impaired individuals) and offer them to all members of the tour. (For more information on accessible labels, see the supplemental section on viewing heights of wheelchair users at the end of this chapter.)

Exhibit Layout. People walking with assistive devices or using wheelchairs may have difficulty turning around during a tour discussion to observe objects behind them or off to the side. Try to select exhibits that allow tour members to see you and most of the objects you are discussing at the same time. Remember also that exhibits on high pedestals or in high, deep horizontal cases may be difficult for an individual in a wheelchair to see. Describe things carefully using the techniques listed in the chapter on visually handicapped people to describe the objects that people cannot see. (For more information, see the supplemental section on viewing heights of wheelchair users at the end of this chapter.)

Handles, Knobs, and Buttons. Mobility impaired people who have difficulty using, or who cannot use, their fingers, hands, or arms may need assistance turning handles and knobs or pushing buttons to activate exhibits or to open doors.

Touchable Objects. Assume that the person knows his own ability to handle objects. Do not discourage him from participating because you think he may have trouble with an activity. He will tell you (without prompting) if he doesn't feel confident about handling an object. If he says he is unable to hold or manipulate an object, offer to show it to him, assist him in manipulating it, and/or demonstrate it for him up close.

Auditoriums. If your tour includes a presentation in an auditorium, make sure there is adequate space for wheelchair users. If not, arrange for the presentation to take place in another room where wheelchair users can be accommodated more easily.

Restrooms. Persons walking with assistive devices or using wheelchairs may need specially equipped rest-

rooms with wider and longer stalls, handrails, and specially mounted toilets, mirrors, towel dispensers, and sinks. If your building does not have such restrooms, the mobility impaired person may require special assistance. Find out directly from the person what method of assistance is best.

Water Fountains. People walking with assistive devices may have difficulty leaning over and operating a water fountain. Many water fountains are mounted too high for an individual in a wheelchair to reach. People with limited hand dexterity may not be able to operate the fountain's control handle. The easiest solution is to provide the person with a cup of water upon request.

Begin Your Tour at an Entrance

If you know that someone who is mobility impaired will be joining your tour, try to begin your tour where the person will enter the building or site.

Be Ready to Offer Assistance

- Make a general offer of assistance to the entire group at the start of the tour. If no one takes you up on your offer, don't be offended; never assist unless you are asked to or if your offer is accepted. If someone does request assistance, ask how you can best help him.
- Offer wheelchairs to anyone who wants one if they are available. Some mobility impaired people who walk with assistive devices may prefer to use a wheelchair on a tour. Assist people in getting the wheelchairs and wait until they are ready before starting your tour.
- If a person in a wheelchair asks you to push his chair during the tour, decide whether or not you would feel comfortable doing this. If you have back problems or do not feel strong enough to push someone throughout the tour, it would be better to decline. Never say *yes* because you're afraid to say *no*. If you do decide to assist him, it will help you to pace the tour to the wheelchair user's speed, to be more aware of him during the course of the tour, and to aid him in reaching the front of the group each time it reassembles. If you decide not to assist him, try to find someone on the staff or in the group who will.

Provide Rest Stops

People who walk with assistive devices may need frequent rest stops during a long walking tour. If benches and chairs are not available along the route you've planned, either provide them on a temporary basis or plan an alternate route. Rest periods are a good time for you to recap your tour or discuss new information.

Allow Extra Travel Time Between Exhibits

Some mobility impaired people may need this time to catch up with the rest of the group. You might announce at the start of the tour that you will give people several minutes to look over each new exhibit area before you begin speaking. This will allow mobility impaired individuals to discreetly catch up and position themselves at the front of the group before you begin.

Allow Mobility Impaired People to Drop Out of the Tour

Some people may not be able to stay with the group until the tour is over but may be embarrassed about leaving early. If you don't want to shorten your tour, make an announcement at the start that people are free to leave whenever they like (provided this does not conflict with other regulations). If building regulations do not permit this, announce one or more "breaking points" from which tired visitors can be escorted by another docent to the starting or ending point.

Use Elevators If They Are Available

If your tour includes a group of mobility impaired people, try to keep walking to a minimum, avoid stairs, and use wheelchair lifts or elevators. If elevators are located on the opposite end of the building from your tour, try to change the route of the tour in order to use the elevator for your group's transportation to the different floors. If it is impossible to do this, tell the mobility impaired person the problem; direct him to the elevator and suggest that he meet you and the group at the exhibit *following the one you will present next*. That way the group will not be held up and the wheelchair user will not become permanently separated from the tour. Find out when he may next join another group to hear the part of the tour he missed.

Make Program Changes When Necessary

If a mobility impaired individual or group of individuals cannot be provided with access to an exhibit, consider the following:

- Select several models or representative artifacts to bring to the mobility impaired person.

- Substitute other, more accessible exhibits.
- Use photographs, slide shows, films, or video presentations of the inaccessible exhibit.
- Offer self-guided tours (audio or printed) to mobility impaired people who wish to set their own pace, or who must drop out of a regular tour but still want information about it.

Be Aware of the Wheelchair User's Perspective

- When speaking to a person in a wheelchair for more than a few minutes, sit down so he will not have to constantly look up at you.
- Remember that the personal space of a wheelchair user includes the chair, so don't lean on it or stand too close to it.
- If you are pushing someone in a wheelchair through a noisy area, do not deliver tour information at the same time. He may not be able to hear you since you are directly behind him and facing in the same direction. (Remember this also when conversing with a group while walking.)
- Try to show objects or other visual aids at the eye level of a wheelchair user.

Never Take Aids Away From a Mobility Impaired Person

Allow him to keep his crutches, walker, wheelchair (if the person transfers to another chair), or cane nearby when he is sitting down; these *are* his mobility and without them, he would be very vulnerable during an emergency. If it is *absolutely necessary* to move the aid (e.g., in an auditorium where it could become a hazard to someone else), store it as close by as possible and make sure the person knows exactly where it is.

Never Talk through Others to Mobility Impaired People

They can speak for themselves; don't ask others what they want or think. Also, feel free to use terms like *walk* and *run*; they are in the vocabularies of mobility impaired people, too.

Practice Exercises

Exercise 1. Go through your tour route by yourself, with another docent, or, if possible, with someone who has a mobility impairment and is a wheelchair user, walks with a slower gait, or uses a mobility aid such as a cane, braces, or crutches. Analyze your tour for hazards and barriers to people with mobility impairments; then sketch out alternate routes and programming ideas. You might find that the alternatives are better and more efficient.

Exercise 2. Go through your tour, analyzing it for its pace and number of rest stops or discussion areas.

- Think of ways that you could introduce information without walking to all of the areas that illustrate it (e.g., mention where certain areas are, illustrate them with photographs, and suggest that people visit them after the tour).
- Look at the number and location of rest stops. Examine the quality of the seating (e.g., the seats should have firm backs and armrests).
- Think about what introductory and recap material you can offer while people are resting.
- Decide how much you can afford to slow the pace without boring people.

Emergency Procedures

In an emergency, follow procedures already established for your building or institution. A person with a mobility impairment, however, may require additional attention in a crisis. Here are some procedures to follow in addition to standard ones.

If the mobility impaired person is injured:

- If a mobility impaired person falls (but does not seriously hurt himself), offer assistance. Many people can regain an upright position themselves and will need no help. However, if the person accepts your offer, ask him how to best assist. Some tips that may assist you both:

  The mobility impaired person may be able to get back to a standing position by pulling himself up on the back of a chair or bench. Offer to bring over a chair and stabilize it with your body by sitting on it or by bracing it with your arms and legs.

  Most people find it easier to stand up from a starting position on their hands and knees. You may be able assist a person by getting him onto his stomach

and, if possible, onto his knees. Use his shoulders and the back of his belt as points from which to pull him. Remember, however, to ask before you act.*

If the person is wearing leg braces when he falls, he may have problems with the braces locking at the ankle, knee, or hip joint. In order to assist, be aware that lock-release mechanisms are usually located near the joints themselves.

- Do not attempt to transfer a person from a wheelchair unless you have been trained in doing so. You can cause severe injury by carrying out this procedure improperly. If someone must be moved from his wheelchair, be aware that many people have lap trays attached to the front of their wheelchairs. A lap try may be removed by swinging it away from or by lifting it off of the arms of the wheelchair.

- If the person must be taken to the hospital, make sure his mobility aids (e.g., wheelchair and crutches) are sent with him.

If the building must be evacuated:

- In any evacuation procedure, offer to push a person who is a wheelchair user out of the building or to a safe area.** If a person is ambulatory but moves slowly, offer to get a museum wheelchair for him in order to proceed more quickly to an exit.

- If there is a fire and elevators are not usable, direct the mobility impaired person to the nearest major stairway. If your museum has evacuation equipment for wheelchair users, know where it is and how to use it. If there is no equipment available, make sure the person gets to the stairwell; then locate a guard, other trained personnel, or a firefighter and tell him exactly where the disabled person is waiting. The wheelchair user may opt to be carried down by the firefighters or he may choose to get out of his chair and "bump" down the stairs (sitting on the stairs and sliding down one stair to the next one) if he has sufficient upper torso strength.

*If you are assisting someone with rheumatoid arthritis, remember that his joints may be very painful. Do not hold someone with this disability by the shoulder, elbow, or other joints. It is extremely important to question this person on how to assist him before acting.

**Some recently constructed buildings have stairwells that are designed to keep out fire and smoke; these stairwells are often referred to as "safe areas."

Supplemental Information

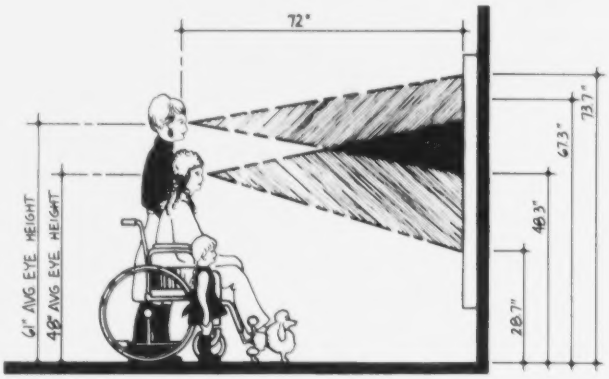
The following illustrations and information are reprinted with permission of Barrier Free Environments, Inc., and the National Endowment for the Arts.

Comfortable Viewing Zones

Signs and Labels. For both standing and seated people, there is a comfortable viewing zone of 19" within which text can be displayed if printed in large type. This comfortable viewing zone is between 48" and 67" above the floor. 54" to center is a good height for mounting signs and labels on the wall.

⅝"-high letters can be read comfortably by sighted people at a distance of more than 6 feet.

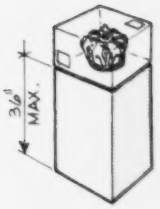
Smaller type sizes customarily used in exhibition displays can be read at a distance of 4 feet if printed in maximum contrast. The visual zone reduces to 8-⅓" when displayed between 52" and 60" from the floor.

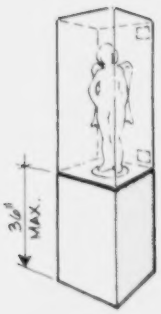


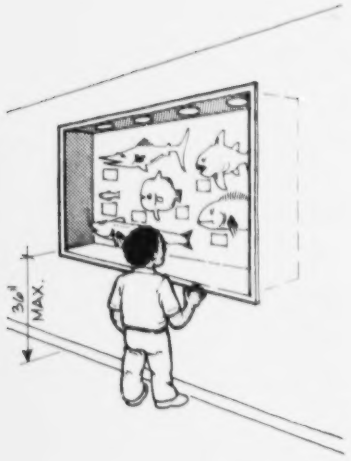
Display Cases. Display cases should allow short or seated people to see the contents and the labels.

If the sides of the case are transparent, the *bottom* of the case may be mounted as high as 36" above the floor, but never any higher. Cases with transparent sides are usually wall-mounted, or free-standing on a solid base.

Floor-mounted cases often have solid sides and can only be viewed from the top. These cases should be no higher than 36" to the *top* of the case so short and seated people can see down into the case. It is more important that the top of the case not exceed 36" than that wheelchair clearance be provided underneath. However, all display cases must have enough

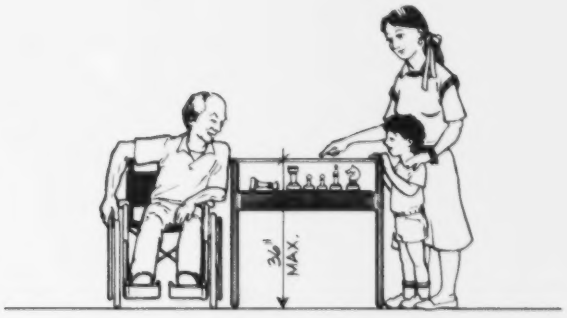






clear floor space beside them for people in wheelchairs to pull up close to the display.

Labels should *never* be flat on the bottom of cases. Labels can be mounted vertically on the back wall or the outside of the case; two labels at different heights may be needed if the case is very large. For low, glass top cases, one label may be mounted flat on the top for standing people who are viewing the contents from above, and one label may be mounted on the vertical surface of the display.



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7

People with Cerebral Palsy

Although cerebral palsy (also called CP) has existed for centuries, it was not clearly defined in medical literature until 1862, when W. J. Little, an English orthopedic surgeon, realized that difficulties at birth could result in neurological impairments. The medical profession continued study of the disability with limited success in decreasing the number of cases that occurred annually. During the past twenty-five years, however, discoveries in the areas of fetal oxygen deprivation during pregnancy, the development of a vaccination against maternal rubella, and the establishment of screening procedures of babies at high risk for developing neurological disabilities have dramatically reduced the number of children born with cerebral palsy.

According to the United Cerebral Palsy Association, today approximately 750,000 Americans have the disability, and 7,000 to 9,000 babies are born each year with central nervous system disorders which result in cerebral palsy. In addition, between 1,200 and 1,500 preschool-aged children annually acquire the disability.

Cerebral palsy may be broadly described as a nerve and muscle disorder that results from damage to the brain. The word *cerebral* refers to the brain and the word *palsy* to the lack of muscle control that is a symptom of the disability. The National Institute of Neurological and Communicative Disorders and Stroke states that, ninety percent of the time, cerebral palsy is a nonprogressive disability that occurs before, during, or shortly after birth. It may result from problems prior to birth, such as maternal illness (e.g., German measles) or intrauterine infection, or it may result from problems during birth, such as lack of oxygen or a head injury due to forceps. Cerebral palsy may also occur during the first years of life due to infections such as meningitis, head trauma, and brain damage caused by lead poisoning.

The most common characteristics of cerebral palsy are stiff and/or involuntary movements of the head, arms, and legs; balance problems when walking, standing, or sitting; and difficulty with speaking. Because of his impairments in communication and his motor disorders that result in facial grimacing or random body movements, a person with cerebral palsy is often mistakenly thought of as being retarded or mentally ill. While many people with cerebral palsy do have these additional disabilities, many also do not. The range of intelligence levels and adaptive behaviors among people with cerebral palsy is as wide as it is in the rest of the general population.

Other disabilities that people may have in addition to CP include hearing impairments, visual handicaps, tactile and olfactory impairments, and learning disabilities. (For more information, see the sections on these individual disabilities.)

Effects of the Disability

Mobility Impairments

A wide range of mobility impairments are associated with cerebral palsy. While one individual may have a slightly uneven gait or limited use of one hand, another may require a wheelchair because he has extremely limited voluntary movement. Cerebral palsy may affect only one side of the body; one arm and both legs; mainly the lower limbs; all four limbs; or both sides of the body but more severely in the arms than in the legs.

Movement Control Disorders

There are four types of movement control disorders under the heading of cerebral palsy. Although it is not

necessary to know the specific characteristics of each, it is helpful to understand the different ways CP affects people's motor abilities.

1. *Spasticity*—This is the most common type of movement disorder where the muscles tend to contract and become stiff or tense, especially when put under stress. In some cases, the back leg muscles contract and pull the heel up, causing the individual to walk on tiptoe.

2. *Athetosis*—The person with athetoid cerebral palsy moves in a constant and involuntary manner. His hands may twist, his facial features may contort, and his tongue may move randomly in his mouth. His speech is often intelligible only to people who know him. These involuntary movements become more frequent and exaggerated when the individual is under stress.

3. *Ataxia*—This disturbance causes a loss of equilibrium that can affect walking and standing or even directing the movement of the limbs. A person with ataxia may sway when standing, walk with feet wide apart to prevent falling, and have difficulty moving and picking up objects.

4. *Mixed*—One or more of the above types of motor disorders may be present in a person with cerebral palsy. When the disorders exist in combination, the symptoms are said to be mixed. The severity of these symptoms varies; however, one disorder usually dominates the others.

Degrees of Severity

As with other disabilities, there are degrees of severity in cerebral palsy. Each of the four movement control disorders explained above may exist in mild, moderate, or severe forms and may affect people in the following ways:

Mild form. Persons who are mildly disabled can walk and can use their hands (even when they are affected) to accomplish everyday activities. However, fine precision movements may be difficult for them.

Moderate form. Persons who are moderately disabled have difficulty speaking clearly and performing gross and fine motor movements. Their ability to walk and help themselves may be impaired, but they can perform the usual activities of daily living with little or no assistance. They may use braces or other assistive devices.

Severe form. Persons who are severely disabled have limited ability to walk, to speak, and to perform daily living activities. They often use wheelchairs and may require some degree of attendant care for personal hygiene, eating, and mobility.

Seizures

Reports concerning the incidence of seizures among people with cerebral palsy vary; however, many people with the disability have a seizure at some time in their lives. These are usually "petit mal" or mild seizures during which the person may simply lose contact with the environment for a short time, stare off into space, and then recover. A person may also have a "grand mal" seizure which involves loss of consciousness and convulsions. With medication, however, it is now possible to prevent the great majority of people with cerebral palsy from having seizures. (For more information on seizures, see the emergency procedures section in the chapter on mental retardation and the resources section at the end of the manual.)

Communication

Communication can be a serious problem for many people with cerebral palsy. Speech impairments and difficulties with writing and reading may make communication difficult.

A high percentage of people with cerebral palsy have some degree of speech impairment, ranging from minor articulation problems to difficult-to-understand speech or no speech at all. In general, a direct correlation exists between the degree of mobility impairment and the severity of the speech impairment experienced by a person with CP: individuals with severe mobility impairments are more likely to have severe speech impairments. There is, however, no correlation between a person's ability to speak and his ability to understand speech—even when a person's speech is absent, he probably comprehends everything he hears.

People who do not have intelligible speech may use alternative methods of communication. These include (1) simple signs that demonstrate an individual's needs and wants; (2) communication boards or communication books containing words and symbols that can be used to construct sentences; and (3) microcomputers that are programmed with extensive vocabularies that can be printed out or verbalized by synthesized speech. If a person is unable to use his hands, he may use a head stick (a pointer attached to a visor or helmet) or other device for pointing to and typing out words, as well as a variety of other methods for indicating word and concept choices. Communica-

tion by these methods can be effective, but it is necessarily slower and requires more patience from both participants in the conversation. (For more information on alternative methods of communication, see the section on assistive devices for persons with cerebral palsy in this chapter.)

Fine motor problems, visual impairments, and perceptual problems may cause someone with cerebral palsy to have difficulty with writing. Involuntary or counterproductive movements make holding and using a writing instrument difficult. Visual impairments and perceptual disabilities can cause letters to be poorly formed and handwriting to flow unevenly across the paper. Finally, perceptual problems may affect hand-eye coordination, depth perception, and figure-ground perception—all important to the task of writing.

A person with cerebral palsy may also have problems in the area of reading and language development. Visual impairments and visual perceptual problems make reading skills difficult to acquire; hearing impairments, auditory perceptual problems, and social isolation often cause language skills to develop slowly and in a more limited fashion.

Education and Training

In the past, many people with cerebral palsy were institutionalized because of improper identification procedures, misunderstandings about the disability, and lack of school programming. Today, the picture is quite different. A variety of educational opportunities are available to individuals with cerebral palsy including special schools or special classrooms in regular schools. Some children with cerebral palsy are mainstreamed full- or part-time into regular classes with nondisabled peers. The student with CP may receive the services of a variety of specialists including special education teachers, occupational therapists, physical therapists, and speech therapists.

While in high school, the person with cerebral palsy may pursue a course of study leading to college and enter any number of professional fields such as law, engineering, or business, or he may choose vocational training that readies him to work as a skilled laborer in a variety of areas.

Some individuals, however, who are very severely disabled by cerebral palsy find it impossible to enter into competitive employment. Instead, they may work in sheltered workshops, contract to do home-based jobs (e.g., typing addresses onto envelopes), or pursue such areas as computer programming to further their educations and strengthen their independence.

Aids for Individuals with Cerebral Palsy

Mobility Aids

People with cerebral palsy may use any of the assistive devices used by mobility impaired persons, including braces, special shoes, canes, crutches, walking frames, and wheelchairs. (For more information, see the section on mobility aids in the chapter on mobility impairments.)

Communication Aids

As the technology in this area develops, there is an ever-growing variety of communication aids available to people with CP. The following examples are some of the aids you might see a visitor using in a museum. Although you may need training to effectively communicate with several of these, it will be helpful to familiarize yourself with the different kinds of aids and how they work.

Communication boards. Individuals with cerebral palsy who have limited ability to communicate through their own speech may use communication boards to convey information. Using their hands, eyes, or head stick/head light beams to point to fixed letters, words, symbols and/or pictures on a communication board, they may compose phrases and sentences. The communication board may be a homemade device of wood that sits like a tray on the arms of a person's wheelchair or it may be a commercially manufactured board made of clear plastic with paper cards attached.

To use the wooden communication board, the individual points out his word/idea choices (using his hand, head, or eye movements) to the receiver who sits alongside or across from him. To use the clear plastic board, the speaker sits on one side of the board and indicates with his eyes which words he is choosing; the receiver sits on the other side and watches through the board for the speaker's eye movements and choices. (The clear plastic board is primarily for individuals who do not have the ability to move their arms or heads voluntarily.) The procedure involved in using a communication board is slow, but it offers accurate communication for someone who is severely speech impaired. This system requires practice in order to be used easily.

Head sticks, head light beams. Individuals who are able to move only their heads voluntarily may use vi-

sors, helmets, and other headgear that have pointers or battery-powered lights affixed to the front. These devices allow the individual to point to choices on a communication board and to operate computers and typewriters.

Talking paddle. This board offers three choices (i.e., yes, no, and question mark) that a person may use to answer questions requiring one-word responses. Another version of this board, for nonreaders, has a smiling face, a frowning face, and a question mark. To use these boards, the individual with cerebral palsy simply points to his selected answer and shows it to the questioner.

Computerized devices. Sophisticated computer technology has now been developed and adapted to provide people with severe speech impairments with hundreds of words and portions of words to express themselves. Programmed information and instructions allow people to type and store material with much greater ease and efficiency than with a typewriter. Using computers, these people can process long and complex messages and communicate on a level commensurate with their intelligence.

One example of a simple electronic device used by people with cerebral palsy is the Canon Communicator (TM), a small, hand-held calculator-like device that can be used to spell out messages. The Communicator has keys for each letter of the alphabet; when typed out, the message either appears in an LED display or is printed out on a paper strip. The benefit of the machine is that it is completely portable and so can be used for communication under most circumstances.

Terminology

Cerebral palsy A person who has cerebral palsy is someone who has a nerve and muscle disorder resulting from a neurological impairment that may occur before, during, or up to two years after birth.

Remember that disabled persons are individuals and do not move, think, or act *en masse*. Therefore, they should be referred to as *disabled people*, not *the disabled*. *People with cerebral palsy* should be referred to that way. Certain phrases that are frequently used to describe people with cerebral palsy evoke inappropriate responses of pity or awe. Therefore, do not refer to a person with cerebral palsy as:

a cerebral palsy or CP
cerebral palsied
a spastic
a cripple
confined to a wheelchair
a victim of. . .
afflicted by. . .
sentenced to a life of. . .
almost normal
overcoming insurmountable odds
courageous
superhuman

Adapting Your Tour

Evaluate the Accessibility of the Facility

Make your building as accessible as possible to people with cerebral palsy. Even if such individuals are not participating in your tour, you should always know the location of elevators, wheelchair lifts, and ramps; emergency and other exits; audio-visual equipment and programs; and artifacts or models that could be brought to an individual who is unable to reach an exhibit. People with cerebral palsy who are also mobility impaired use a variety of assistive devices, including wheelchairs, canes, crutches, and artificial limbs, so be sure to evaluate accessibility for all types of aids. The following may present special problems for the individual with CP:

Stairs and Curbs. A person who walks with an assistive device may have trouble with stairs and curbs. Stairs should be smooth but not slippery, and should have edges without lips. At least one side railing should run the full length of the staircase, extending twelve inches beyond the top and bottom stairs. Elevators may be the preferred means of moving from level to level; however, if there are no elevators, or if stairs are more convenient, the visitor should be given the option to climb.

For an individual with cerebral palsy who has a severe lower-limb mobility impairment, stairs present an even greater problem; an elevator or wheelchair lift may be essential. If these are not available, program changes (such as slide or video presentations of upper level exhibitions or moving a second-story activity to the first floor) will be necessary. Outside, curb cuts will aid independent travel; if there are no curb cuts, the individual may need special assistance. (You should not attempt to maneuver a person's wheelchair up a step or curb without training or careful instruction from the wheelchair user.)

Floors, Carpets, and Ramps. For an individual walking with an assistive device, slippery surfaces (such as a highly polished floor) are extremely hazardous. This visitor may need a wheelchair or personal assistance to proceed safely through the area. Steep grades, rough or uneven surfaces, and throw rugs or runners may also be dangerous; the person may need assistance if these areas cannot be avoided.

For an individual in a manually operated wheelchair, deep-pile carpeting, rough or uneven surfaces, and steep grades or ramps may make independent travel difficult; the visitor may need someone to assist him through the area or to help him find an alternate route.

Narrow Spaces. A wheelchair user needs a specific amount of space to maneuver through and turn around in. For example, doorways must be at least thirty-two (preferably thirty-six) inches wide and a turning space must have a diameter of sixty inches. If doorways are not wide enough or if exhibit space is too limited or cluttered to accommodate a wheelchair user, you will need to adapt your program.

Labels and Signs. A person in a wheelchair has a lower line of vision than a person who is standing. Therefore, signs and labels positioned for the standing viewer may be too high for him to read. For the benefit of persons with balance problems, labels should not be located near the top of a flight of stairs or in other areas that may be dangerous.

If labels are a problem, provide label texts (the same large-print labels that are used with visually impaired individuals) and give them to anyone who wants them. (For more information on viewing heights of wheelchair users, see the supplemental section in the chapter on mobility impairments.)

Exhibition Layout. People walking with assistive devices or using wheelchairs may have difficulty turning around during a tour discussion to observe objects behind them or off to the side. Try to select exhibitions that allow tour members to see you and most of the objects you are discussing at the same time. Remember also that exhibits on high pedestals or in high, deep horizontal cases may be difficult for an individual in a wheelchair to see. (See the supplemental section on viewing heights of wheelchair users in the chapter on mobility impairments.)

Handles, Knobs, and Buttons. People with cerebral palsy who have limited hand or arm muscle control may have difficulty operating knobs, buttons, and handles throughout the museum. Activating exhibitions, turning doorknobs, turning on water fountains, and participating in activities requiring other fine motor movements may be a problem for them. Offer assistance in manipulating these objects.

Auditoriums. If your tour includes a presentation in an auditorium, make sure there is adequate space for wheelchairs users. If not, arrange for the presentation to take place in another room where people in wheelchairs can be accommodated more easily.

Restrooms. Persons walking with assistive devices or using wheelchairs may need specially equipped restrooms with wider and longer stalls, handrails, and specially mounted toilets and sinks. If your building does not have such restrooms, the individual with CP may require special assistance. Find out directly from the person what type of assistance is best.

Water Fountains. People walking with assistive devices and those with limited hand or arm muscle control may have difficulty operating a water fountain. Also, many water fountains are mounted too high for an individual in a wheelchair to reach. The easiest solution is to provide the person with a disposable plastic cup for water.

Begin Your Tour at an Entrance

If you know that someone who has cerebral palsy will be joining your tour, try to begin your tour where the person will be entering the site.

Be Ready to Offer Assistance

- Make a general offer of assistance to the entire group at the start of the tour. If no one takes you up on your offer, don't be offended; never assist unless you are asked or unless your offer is accepted. If someone does request assistance, ask how you can best help him.
- If an ambulatory person with cerebral palsy asks for assistance in walking from exhibit to exhibit, offer your arm rather than taking his. You will then serve as a stabilizer as opposed to a force pulling the individual off balance.
- Offer wheelchairs, if available, to anyone who wants them. Some people with cerebral palsy who walk with assistive devices may prefer to use a wheelchair on a tour. Assist people in getting the wheel-

chairs and wait until they are ready before starting the tour.

- If a person in a wheelchair asks you to push his chair during the tour, decide whether or not you would feel comfortable doing this. If you have back problems or do not feel strong enough to push someone throughout the tour, it would be better to decline. Never say *yes* because you're afraid to say *no*. If you do decide to assist him, it may help you pace the tour to the wheelchair user's speed, to be more aware of him during the course of the tour, and to aid him in reaching the front of the group each time it reassembles. If you decide not to assist him, try to find someone on the staff or in the group who will.

Plan Your Tour Route to Include Elevators

If the person with cerebral palsy has a severe lower-limb mobility impairment, avoid stairs and use elevators whenever possible. If elevators are located a great distance from your tour route and you cannot change the route, explain this to the mobility impaired person. Direct him to the elevator and suggest that he meet you at the exhibit *following the one you will present next* (that way the group will not be held up and the wheelchair user will not become permanently detached from the group); find out when he can join another group to catch the part he missed.

Provide Rest Stops between Exhibits

People with cerebral palsy may tire easily and need frequent rest stops during a long walking tour. Rest areas should have furniture with armrests and backs, as many people need something to support their backs when sitting and to support their rising motion when moving to a standing position. If chairs are not available along the route you've planned, either provide them on a temporary basis or plan an alternate route. Rest periods are a good time for you to recap your tour or discuss new information.

Allow Extra Travel Time between Exhibits

People with cerebral palsy may have difficulty breathing if you move too quickly from room to room. Allow time for these people to catch up with the group. You might announce at the start of the tour that you will give people several minutes to look over each new exhibit area before you begin speaking. This will allow individuals with CP to discreetly catch up and position themselves at the front (if they are in wheelchairs) before you begin.

Allow People with Cerebral Palsy to Drop Out of the Tour

Some people may not be able to stay with the group until the tour is over but may be embarrassed about leaving early. If you don't want to shorten your tour, make an announcement at the start that people are free to leave whenever they like (provided this does not conflict with other regulations). If building regulations do not permit this, announce one or more "breaking points" from which tired visitors can be escorted by another docent to the starting or ending point.

Include Touchable Objects in Your Tour

Assume that the person with cerebral palsy knows his own ability to handle objects. Do not discourage him from participating because you think he may have trouble with an activity. He will tell you without prompting if he doesn't feel confident about handling an object. If he is unable to hold or manipulate an object, offer to show it to him, assist him in the manipulation, and/or demonstrate it up close.

Be Aware of the Wheelchair User's Perspective

- Sit down when speaking for more than a few minutes to a person in a wheelchair so he will not have to constantly look up at you.
- Remember that the personal space of a wheelchair user includes the chair, so don't lean on it or stand too close to it.
- If you are pushing someone in a wheelchair through a noisy area, do not deliver tour information while walking. He may not be able to hear you since you are directly behind him and facing in the same direction. (The same suggestion holds true for simple conversations.)
- Show objects or other visual aids at the eye level of the wheelchair user.

Never Take Aids Away from a Mobility Impaired Person

Allow him to keep his crutches, walker, wheelchair (if he transfers to another seat), or cane nearby when he is sitting down; these *are* his mobility and without them, he would be very vulnerable during an emergency. If it is *absolutely necessary* to move the aid (e.g., in an

auditorium where it could become a hazard to someone walking through the aisle), store it as close by as possible and make sure the person knows where it is.

Communicate Directly with a Person Who Has Cerebral Palsy

Do not speak to him through his friends or family. If someone in the group (who is not associated with the person) tries to speak for him, try to deflect the intrusion, maintain eye contact with the disabled person, and continue speaking directly to him. Allow extra time when communicating with a person who has cerebral palsy (you may need to converse using a communication aid). If you do not understand the person's comment or question, ask him to repeat it; or repeat it yourself and ask for confirmation. If you still don't understand, ask the person's permission to seek assistance from a family member or a friend.

Adapt Tour Materials If Necessary

Some individuals with cerebral palsy may also be mentally retarded or may have been institutionalized for many years. These people may need to have the content of their tour materials simplified. (See the chapter on mental retardation for specific information.) However, remember that many people with cerebral palsy do not have the additional disability of mental retardation and learn at an average or above average rate. Never assume that any visitor with CP is also mentally retarded.

Make Program Changes If Exhibitions Are Inaccessible

- Select several models or artifacts to bring to the person.
- Substitute other, more accessible exhibits.
- Use photographs, slide shows, films, or video presentations of the inaccessible exhibit.
- Offer self-guided tours or comprehensive brochures to those people who wish to set their own pace, or who must drop out of a regular tour but who still want information about it.

Practice Exercises

Exercise 1. Go through your tour route by yourself, with another docent, or (if possible) with someone who has cerebral palsy and who uses a wheelchair or crutches, or walks with a slower gait. Analyze your tour for hazards and barriers to people with cerebral palsy; then sketch out alternate routes and programming ideas. You might find that the alternatives are better and more efficient.

Exercise 2. Go through your tour, analyzing it for its pace and number of rest stop/discussion areas.

- Think of ways that you could introduce information without walking to all of the areas that illustrate it (e.g., mention where certain areas are, illustrate them with photographs, and suggest people visit them after the tour).
- Look at the number and location of the rest stops. Examine the quality of the seating (e.g., seats should have firm backs and armrests).
- Think about what introductory and review material you can offer while people are resting.
- Decide how much you can afford to slow the pace without boring people.

Emergency Procedures

In an emergency, follow procedures already established for your building or institution. However, a person with cerebral palsy may require additional attention in a crisis. Here are some procedures to follow in addition to standard ones.

If the person with cerebral palsy has a seizure:

A seizure is a neurological malfunction involving an uncontrolled electrical reaction in the brain. This temporary change in functioning causes an unusual amount of electrical energy to pass between cells and overloads a part or all of the brain's system. A seizure may involve muscle convulsions, partial or total loss of consciousness, mental confusion, and loss of control of some bodily functions. Medication can help control the frequency of seizures.

There are two types of seizures, convulsive and nonconvulsive. Convulsive seizures are easier to recognize and require more assistance. The primary characteristics of a convulsive seizure are a loss of consciousness and muscle jerks.

The most important thing to remember if someone has a convulsive seizure is not to panic—remain calm and follow these basic rules:

- Place a folded coat under the person's head to prevent him from hitting it on the floor.

- Try to protect the person from hitting objects or furniture around him (by moving the objects) but do not restrain him. The seizure must run its course.
- Loosen his tie or shirt collar and try to turn him on his side to keep his air passage clear.
- *Do not* put hard objects into his mouth or try to hold his tongue—he cannot swallow his tongue, but he can damage his teeth or your fingers by biting down forcefully.
- Do not try to get the person to drink anything during or right after the seizure.

If possible, check the person's wrists or neck for medic alert identification. If he is wearing any, it indicates the presence of a medical condition that may be related to his present physical state. It may be necessary to contact trained personnel for further assistance.

For more complete information on convulsive and nonconvulsive seizures, see the chart provided in the resources section at the end of this manual.

If the person with cerebral palsy is injured:

- Take the time to understand what the person is saying. People with speech impairments tend to have more difficulty talking when they are under stress. Calm the person and remain calm yourself.

  To expedite understanding:

  Ask a series of yes-or-no questions to find out about the location and extent of the injury.

  Locate the person's communication aid, if appropriate, and use it.

  Ask the person to point, with his hands, head, or eyes, to the injury or the location where the accident occurred.

  Try to "read" his facial expression and ask yes-or-no questions related to what you believe you are interpreting.

  If there is someone else who witnessed the accident or seems to understand what the person with CP is saying, enlist his assistance. Because the situation may be an emergency, this is the one time you may bypass getting the disabled person's permission for interpretation.
- If a person with cerebral palsy falls (but does not seriously hurt himself), offer assistance. Many people can regain an upright position themselves and will need no help. However, if the person accepts your offer, ask him how to best assist. If you have difficulty understanding his instructions, here are a few guidelines to follow:

  The person with CP may be able to get back to a standing position by pulling himself up on the back of a chair or a bench. Offer to bring over a chair and stabilize it with your body by sitting on it or by bracing it with your arms and legs.

  Most people find it easier to stand up from a starting position on their hands and knees. You may be able to assist a person by getting him onto his stomach and, if possible, onto his knees. Use his shoulders and the back of his belt as points from which to pull him. Remember, however, to ask before you act.

  If the person is wearing leg braces when he falls, he may have problems with the braces locking at the ankle, knee, or hip joint. In order to assist, be aware that lock-release mechanisms are usually located near the joints themselves.
- If a person with cerebral palsy begins to choke while drinking, eating, or swallowing his own saliva, you must ascertain whether it is actually an emergency situation. Some people who have severe CP have difficulty swallowing and may cough or make choking sounds whenever they swallow. If it is not serious, it will resolve itself in about fifteen seconds. If the choking continues beyond this time, use standard emergency procedures immediately.
- Do not attempt to transfer a person from a wheelchair unless you have been trained in doing so. You can cause severe injury by carrying out this procedure improperly. If someone must be moved from his wheelchair, be aware that many people with cerebral palsy have lap trays attached to the front of their wheelchairs. A lap tray may be removed by swinging it away from or by lifting it off of the arms of the wheelchair.
- If the person must be taken to the hospital, make sure his mobility aids (e.g., wheelchair and crutches) and communication aids (e.g., communication board or communication book) are sent with him.

If the building must be evacuated:

- In any evacuation procedure, offer to push a person who is a wheelchair user out of the building or to a safe area*. If a person with CP is ambulatory but moves slowly, offer to get a museum wheelchair for him in order to proceed more quickly to an exit.

* Some recently constructed buildings have stairwells that are designed to keep out fire and smoke; these stairwells are often referred to as "safe areas."

- If there is a fire and elevators are not usable, direct the person with cerebral palsy to the nearest major stairway. If your museum has evacuation equipment for wheelchair users, know where it is and how to use it. If there is no equipment available, make sure the person with cerebral palsy gets to the stairwell; then locate a guard, other trained personnel, or a firefighter and tell him exactly where the disabled person is located.

Reference Notes

p. 55 STATISTICS RELATED TO PEOPLE WITH CEREBRAL PALSY: *Cerebral Palsy—Facts and Figures*, A fact sheet published by the United Cerebral Palsy Associations, November 1982.

p. 55 WHEN CEREBRAL PALSY CAN OCCUR: Office of Scientific and Health Reports, National Institute of Neurological and Communicative Disorders and Stroke, *Cerebral Palsy—Hope Through Research* (Washington, D.C.: National Institutes of Health, December 1980), p. 2.

pp. 61–62 TYPES OF SEIZURES AND ASSISTANCE TO OFFER: Epilepsy Foundation of America, *Epilepsy: Recognition and First Aid* (Landover, Maryland: Epilepsy Foundation of America, 1973), no page.

8

People with Mental Illness

For most people who are mentally ill, museum tours can be rich and enjoyable experiences. Yet frequently they cannot participate in programs because they are considered unacceptable as visitors. Museum professionals, like many other Americans, are often irrationally afraid of people with this disability, not understanding how mental illness affects behavior; they think that it might be somehow dangerous to include mentally ill people in general programs. One study indicated that some people in the country have become so negative about those with mental illness that they believe such individuals to be less acceptable in public than criminals.

This attitude is unfair because it is based on incorrect information. It has grown over centuries, more as a result of bad press than anything else. In literature, and later in films and television programs, the stereotype of the mentally ill person as a rampaging, brutal killer appears over and over—an image based on little fact and a lot of fear.

This inaccurate picture of a mentally ill person as violent is hard to change. Considering the publicity, it is no small wonder that people fear and even dread those who are mentally ill. Rarely is the other side of the story publicized—the side that shows the great majority of mentally ill people as functioning, contributing members of society. People like President Abraham Lincoln, Prime Minister Winston Churchill, philosopher William James, Senator Thomas Eagleton, and astronaut Edwin "Buzz" Aldrin were all mentally ill at some point in their lives. The rampaging killer image fits none of them, but the attitude created by that image handicapped all of them.

Ninety-eight percent of mentally ill people are neither violent nor wild-looking. In fact, timidity and vulnerability are more likely characteristics. Some individuals with severe mental illness may not attend to personal grooming habits and may appear aggressive or socially inept; but the image of the brutal attacker is a gross distortion that has reinforced resistance to integrating mentally ill persons in community housing, public schools, and museum programs. Most mentally ill museum visitors are gaining control over their lives and are either back in the community or getting ready to reenter it. You may not even be able to identify them, because the majority simply melt into the mainstream of society.

The National Alliance for the Mentally Ill defines mental illness as "a group of disorders causing severe disturbances in thinking, feeling, and relating. They result in substantially diminished capacity for coping with the ordinary demands of life. Mental illness can affect persons of any age—children, adolescents, adults, and the elderly—and can occur in any family."

Most people who have a mental illness are acutely mentally ill; that is, they will have one or two episodes lasting weeks or even years but ending in complete recovery, or they may have several episodes in their lifetimes, each separated by many years. The remaining individuals are chronically mentally ill. People with chronic mental illness have repeated episodes following the initial onset and then periods when the illness is not active. In most cases, treatments are available to control the symptoms, although not to cure the illness.

In other words, mental illness may take on many different forms. For example, a person may experience a very severe depression for two years, during which time he isolates himself from his family and work; he then recovers completely, never to have a depressive episode again. Another may experience three episodes during his lifetime, with ten years between each. Although he becomes nearly incapacitated during each

episode, with each recovery he regains full functioning of his coping abilities. Still another person may have repeated experiences with depression alternating with euphoria. Although there are times when he is not actively mentally ill, the disability continues throughout most of his lifetime. In addition, his capacity for coping with everyday living during these in-between periods progressively diminishes with each new onset of an episode.

For the purposes of this manual, we will focus on people in the last group—those who are chronically mentally ill—when we discuss tour situations, since these individuals will need tour adaptations the most. It is important to note that the description of these individuals in tour situations points out their personality and learning characteristics when they are *not* actively mentally ill. It is rare that a person experiencing an active psychotic episode would come to a museum and join a tour, although even people in active states have periods when they function adequately.

Effects of the Disability

Two of the most common types of mental illness are major affective disorders and schizophrenia. Although some severe personality, anxiety, and behavioral disorders are also classified as mental illnesses, we will only describe the two most common disorders in this manual.

Major Affective Disorders

Major affective disorders cause negative changes in an individual's mood, ability to concentrate, and social behavior. The result may be a debilitating depression that nearly halts one's physical and mental functioning, or it may be the opposite, a manic episode during which a state of elevated energy, great enthusiasm, and irritability can cause the person to act impulsively and indiscreetly. Although major affective episodes usually do not have the long-term disabling effects of schizophrenia, they are a leading cause of suicide.

Major affective disorders may occur once in a lifetime, recur at regular intervals, or become chronic and require medication to control. There is no one known cause for this disorder; however, contemporary research shows possible biological, environmental, and genetic elements that may work alone or in combination to preciptate the psychosis.

Major Depressive Episodes. According to the National Institute of Mental Health, approximately 9.4 million Americans have a depressive disorder severe enough to require treatment. (However, less than twenty-five percent seek professional help.) Those people affected range from children to older adults; women are twice as likely as men to experience depressive episodes.

One who has a severe depressive disorder loses interest and pleasure in activities he normally enjoys and experiences a pervasive sense of sadness and gloom during the active stage of his illness, which sometimes lasts as long as two years. Other symptoms may include (1) sleeping or eating too much or too little, (2) an inability to concentrate and think, (3) excessive or inappropriate feelings of guilt and worthlessness, (4) physical agitation or extreme lethargy, (5) overwhelming fatigue, and (6) serious thoughts of suicide or attempted suicide. A person in a major depressive episode may also be anxious, tearful, irritable, and overly worried about his health. He may have delusions (false beliefs) and some hallucinations (the experience of sounds, sights, or smells that are not based in reality) about his feelings of being persecuted or standing on the brink of destruction.

Manic Episodes. The opposite kind of affective disorder is the manic episode during which an individual's predominant mood is elation or irritability. These manic moods may mix or alternate with depressive moods, but they remain dominant. A manic episode lasts for at least one week and is accompanied by three or more of the following symptoms: (1) hyperactivity, (2) increased talkativeness, (3) speech that moves rapidly from topic to topic, (4) inflated self-esteem, (5) decreased need for sleep, (6) inability to concentrate, and (7) grandiose planning, often with poor judgment regarding potential for serious failure. Although during a manic episode a person may feel great energy and believe he has grand ideas, he may commit impulsive, indiscreet acts that do much damage to himself and those around him. Another important and common symptom of a manic episode is mood swings—moods of depression and elation mixing or alternating within moments or hours of each other.

There are basically three types of treatment to control affective disorders: drugs, electroconvulsive shock therapy, and psychotherapy. About seventy-five percent of the patients treated respond to some treatment or combination of treatments.

Schizophrenia

Affecting approximately 1.5 million Americans, schizophrenia manifests itself in active phases lasting several weeks or months, followed by residual phases that may

last two years or more. People in active stages of schizophrenia have severe thought and perception disorders, including hallucinations and delusions as well as emotional and behavioral changes that negatively affect their ability to work and interact with other people. It is rare that people with schizophrenia ever regain the level of functioning attained before the onset of the mental illness. Each active episode tends to leave increasing residual impairment. The word *schizophrenia* is made up of the Greek words *schizo* (split) and *phrenia* (mind), but it is incorrect to describe people with schizophrenia as having split personalities. The split is really between their *perception* of what exists and the *reality* of what exists.

There is no one definition of schizophrenia; its symptoms vary from person to person and do not remain fixed during an entire active episode. No one symptom is even found in every person and none is exclusive to schizophrenia. People with schizophrenia are often bombarded with stimuli, most of which they cannot sort or filter out. They may have a heightened awareness of sights and sounds, an overwhelming collection of thoughts, and a poor sense of their own bodies' boundaries—their perception of reality is skewed. E. Fuller Torrey, in *Surviving Schizophrenia: A Family Manual*, quotes one patient's description of his reality:

Everything is in bits. You put the picture up bit by bit into your head. It's like a photograph that's torn in bits and put together again. If you move it's frightening. The picture you had in your head is still there but broken up. If I move there's a new picture that I have to put together again.

In addition, people who are actively schizophrenic may experience hallucinations such as hearing unpleasant voices yelling at them; or they may have delusions that someone is broadcasting their thoughts or that they are controlling the thoughts of others. In the midst of all this inner tumult, they may also develop confused language, demonstrate poor memory, become grossly disorganized, and follow illogical lines of reasoning and bad judgment. It is not difficult to understand, then, that people in active episodes of schizophrenia tend to show high levels of anxiety, an inability to concentrate, and a lack of interest in personal appearance. Their brains are overwhelmed with enormous amounts of incorrect and frightening information. Some people just shut down completely and retreat to an unmoving, solitary state; others withdraw but try to maintain at least tentative contact with those around them—in small doses at a safe distance.

It is not known what causes the illness, although there are many theories about genetic, biochemical, nutritional, and environmental factors. One recognized fact, however, is that schizophrenia runs in families. It is theorized, therefore, that a person may be genetically predisposed to the disability; then later in life, his illness is precipitated by stress or by biochemical changes such as those that occur during the onset of puberty. Schizophrenia most often begins during a person's late teens or early twenties, affecting women and men equally. People in the active stage of schizophrenia usually need to be hospitalized, but can be released when the illness goes into a residual phase. Hospital stays are likely to last sixteen to seventeen weeks instead of many years as they did two decades ago.

The most successful treatment for schizophrenia today is with drugs, usually with antipsychotic medication. In the past, many other treatments were tried, including surgery (lobotomies), vitamin therapy, electroconvulsive shock therapy, and insulin coma therapy. Most of these have now been passed over for the more successful and potentially less harmful drug therapy. The main purpose of drug treatment is to reduce the number and severity of the symptoms and to delay their recurrence; there is yet no cure.

Following the initial active episode, some individuals experience occasional symptoms that are milder and more manageable, often controlling the frequency of recurrence with drug treatments. Those who have chronic schizophrenia, however, will continue to experience severe symptoms and may be hospitalized for years at a time or for the rest of their lives. They will continue to have obvious symptoms, such as delusions, hallucinations, thought disorders, and little or inappropriate emotional response. Each relapse takes its toll—leaving the person more intellectually and emotionally disorganized than before. Chronically ill individuals may appear to have less and less interest in their surroundings and interact little, if at all, with those around them. Nonetheless, often they are aware of what is going on around them and are passively absorbing the information. As the mental illness progresses, these individuals frequently withdraw totally, growing more isolated from others, making future active phases more difficult to stave off or manage.

General Characteristics of Chronically Mentally Ill People

Some people with severe chronic mental illness may appear withdrawn and apathetic. They may seem to retreat into a world of their own—sitting for long periods without moving, staring into space, talking to themselves, and acting in ritualistic ways (repeating

over and over the same actions in the same order). If they do become interested in an activity, their attention tends to wander after a short time. This inattentiveness may be caused either by a lack of comprehension due to an inability to process the information or by a difficulty with vocabulary itself. Chronically mentally ill people may also have problems understanding abstract concepts and cause and effect or may be unable to synthesize visual and auditory information (e.g., television programs can be difficult to follow because they require simultaneous auditory and visual comprehension). Because of low self-esteem and lack of self-confidence, someone who is mentally ill may find it easier to give up and ignore the information being presented rather than to admit he does not understand.

In spite of this apparent inability to enjoy and comprehend, chronically mentally ill people can do both. Although they may lack the language to clearly express themselves, they frequently have the receptive abilities to take in most of the information and benefit from it. For this reason, these individuals need staff members who are patient and willing to continue teaching them and conversing with them, in spite of limited positive feedback.

Education and Training

Children in educational settings are usually described as emotionally disturbed, emotionally impaired, or behaviorally disabled, broad terms that are used interchangeably. These are general classifications that may include any of the mental illnesses previously mentioned as well as less severe behavioral disorders.

Students who are categorized as emotionally disturbed are offered a full range of educational opportunities in settings appropriate to their educational and psychological needs. They may be mainstreamed with or without resource assistance, or they may be placed in self-contained classrooms in regular schools or in special private and public schools. Some children still attend schools in residential institutions, but their numbers are diminishing with the current trend to deinstitutionalize children and to keep them in home or homelike environments. In addition, students may receive support services outside the classroom such as individual or group counseling, occupational therapy, and treatment involving the use of medication.

High school or college students who become mentally ill have their studies interrupted by hospitalization and, as a result, may drop out of school. Job training programs as well as psychotherapy and counseling services are offered to recovering individuals to help them develop appropriate work and social skills, which will aid their successful reentry into society and reduce their chances of rehospitalization.

Living Situations

The first U.S. hospital for mentally ill people was established in Williamsburg, Virginia, in 1773. It provided patients with shelter and humane care, becoming the model for similar facilities around the country. Not until the end of the nineteenth century did hospitals for mentally ill people—overcrowded and bureaucratized—become dehumanizing, custodial facilties, their back wards filled with untreated patients. This horrible situation continued well into the 1900s. Only since the middle of the twentieth century has the U.S. government begun to look critically at these conditions.

During the 1960s the concept of closing institutions and reintegrating mentally ill people into society was developed. In 1963, President John F. Kennedy signed into law the Mental Retardation and Community Mental Health Centers Act, which provided federal funds for the establishment of community-based centers designed to offer outpatient and inpatient care, emergency and transitional care, and community education. Large institutional hospitals reduced their number of patients or closed down. Thousands of mentally ill people were affected by the legislation.

The concept of the community-based center failed. First, many centers were never built (the 1963 projections were to develop two thousand centers by 1975; in 1978 there were 608 in existence) and those that were built served mainly people with "coping problems" rather than those who were severely mentally ill. Second, many communities strongly resisted the centers and their clients; community residents feared that former mental institution patients living in the neighborhood would endanger their children and would reduce their property values. Third, reintegrating longtime residents of institutions into the larger society—individuals whose social and independent living skills had greatly deteriorated—was not as easy as was originally thought. As a result, many people ended up homeless, living on the street, and unable to care for or defend themselves.

Today living situations for mentally ill people vary widely. Most individuals in active phases of schizophrenia and some individuals with affective disorders are hospitalized until they recover enough so that they are not dangerous to themselves or to others. People who are chronically mentally ill may still spend most of

their lives either in—or in and out of—hospitals. Some may live with their families, in small (one to six people) or medium-sized (up to twenty people) residential settings (also called halfway houses) that provide twenty-four hour supervision, or in independent or semi-independent apartment complexes and houses. Unfortunately, a large number of people still get little or no care and end up homeless, in jail, or in welfare hotels. Even in the twentieth century mentally ill people still remain the outcasts of society.

Terminology

Mentally ill The general term to describe people who have severe disturbances in thinking, feeling, and relating.

Remember that disabled persons are individuals and do not move, think, or act *en masse*. Therefore, they should be referred to as *disabled people*, not *the disabled*. People with mental illness should be referred to as *mentally ill people*, not the *mentally ill*. Certain phrases used to describe mentally ill people are derisive and insulting. Therefore, do not refer to people with mental illness as:

crazy
lunatics or in the loony bin
mad
psycho
schizo
beserk
suffering from . . .
afflicted by . . .
a victim of . . .

Adapting Your Tour

Treat the Visitor with Respect

When someone who is chronically mentally ill joins your group, act naturally and give him the same respect you offer other vistors. Always remember to talk at a level appropriate to the age of your audience. Maintain eye contact and do not condescend —that attitude will be picked up immediately and resented.

Provide Pretour Materials

Some mentally ill people feel uncomfortable in new environments where people and activities are unfamiliar. They may arrive with preconceived, negative attitudes about the visit, expecting to fail. If possible provide mentally ill people with pretour materials either before the visit or at the beginning of the tour so they will know what to expect. (See the information on pretour materials in the tour adaptation section of the chapter on learning disabilities.)

Clearly State the Rules

Do so at the beginning of the tour. Avoid singling out people who are mentally ill but make sure that the basic rules, such as "do not touch objects in the exhibition," are reviewed and understood. This is especially important if your tour includes emotionally disturbed children.

Present Information Clearly

Because of the possibility that the person will have difficulty synthesizing information and filtering out stimuli, speak slowly and clearly and use precise sentences. Do not shout. In fact, a quiet, low-pitched voice will be more effective. Present ideas one at a time, in an orderly fashion, without tangential comments or inconsistent ideas. Give directions about where to go and make statements about what will happen next. Do not require the mentally ill person to make decisions about what to do; you are the leader and he need only follow you.

Avoid Using Abstract Terms and Concepts

Many mentally ill people have difficulty understanding abstractions unless they are related to concrete examples. Do not assume that mentally ill people have a certain level of understanding or background information; instead, work from the ground up, building carefully on the known to explain the unknown.

Keep Your Tour Well Organized

Try to give your program as much structure as possible. Warn the group when you are about to move from one exhibit or room to another; then make the transition smoothly. Avoid totally unstructured time between exhibits. Also try to maintain a certain amount of flexibility to allow for unexpected interruptions, the need for more repetition, or simple changes in pace.

Shorten the Tour Length

People who are mentally ill may have low energy levels due to the effects of medication or the strain of maintaining socially acceptable behavior and involvement in a new environment. As these visitors begin to tire, their

attention may wander. Therefore, try to avoid long, complex presentations. If the group is composed primarily of mentally ill persons, keep the tour to a maximum of thirty minutes. If there are only one or two mentally ill people on the tour, give them an out: state at the beginning of the tour that anyone choosing to leave before the tour ends may do so. If this is against museum rules, arrange to meet another docent at a predetermined place and time so visitors wishing to leave may be escorted to the beginning or ending location.

Make Your Tours Participatory If Possible

However, do not force anyone to become actively involved. Many people prefer to watch from the sidelines and may feel uncomfortable if pressured to speak or participate in an activity. Strike a balance between activities that are participatory and those that require only observation.

Boost Participant Confidence

Remember that mentally ill visitors may have low frustration thresholds due to low self-confidence or an inability to understand the information offered. Provide at least a few easy activities and praise progress and accomplishments honestly; a mentally ill person—like anyone else—will be suspicious of a compliment offered for frivolous or unworthy efforts.

Include Touchables

If you want people to handle objects, show first how they should be held and manipulated. Repeat information and demonstrations to ensure understanding. As it is difficult for some mentally ill people to pay attention to the object and your commentary at the same time, do not give new information while the object is being passed around. Instead, ask questions or offer comments about the object to each person as he holds or uses it.

Select Quiet Areas of the Site

Keep in mind quiet places around your site where you can take the group to sit and watch or listen without a lot of additional auditory and visual distraction.

Deal Firmly with Inappropriate Behavior

People who are mentally ill may behave in odd or inappropriate ways when they are at your site. They may be restless and aggressive (but *not* destructive), or unassertive and withdrawn. They may say or do things impulsively, talk too loudly, or become overexcited. Be considerate of the individual but do not allow yourself to be manipulated. If he has a family member or friend with him, discreetly ask that person to remedy the situation. If not, try to involve him in an activity to refocus his attention, or remove the source of irritation, if there is one (e.g., asking an individual he feels is annoying him to move). Sometimes it is best just to tell the person (away from the rest of the group) that his behavior is not acceptable and should be stopped.

Keep Participants' Questions on Track

If a person asks a question that is unrelated to the topic, tell him politely that it is not relevant. Assure him that if he wants more information after the tour, you will be happy to assist him then. Be careful, however, not to dismiss an idea too quickly as being away from the point. Listen carefully for a connection; if you do not hear one and the individual cannot offer one fairly quickly, suggest that you discuss the question later.

Listen Sympathetically, Within Limits

If a person tells you about his delusions or hallucinations (remember that they are very real to him), explain simply and politely that you do not hear or see what he does. Do not belabor the point. If he persists, tell him that it is not the appropriate time to discuss the subject. Do not respond by making jokes about his ideas or by being sarcastic—he may miss the inherent contradiction of voice inflection and word meaning and thus become confused and irritated.

Be Aware of Medication Side Effects

Medication used to treat and control certain types of mental illness may cause such side effects as (1) a dry mouth (the person may frequently request a drink of water), (2) erratic muscle movements of the mouth and tongue, (3) inability to control saliva, (3) a need to keep pacing, (4) a lack of energy and stamina, and (5) extreme sensitivity to sunlight. If you know ahead of time that a visitor is taking medication that has side effects, try to avoid putting him into situations where these side effects would present real problems (e.g., walking for a long period of time outside if the person is affected by the sun).

Practice Exercises

Exercise 1. Working in pairs, practice using simple language to describe exhibitions and works of art to

mentally ill individuals. While one docent describes an object or work of art, the other should listen for the following:

high interest information
length of sentence (short)
sentence structure (simple)
use of complete sentences
synonyms for difficult vocabulary
introduction/definition of new vocabulary
tone of voice (eliminate a sing-song quality and overtones of condescension)

Exercise 2. In a room or exhibition, select three objects that you could easily relate to visitors' lives. Practice talking about these objects in this way. Next, think of ways you could involve the audience in relating to each object. For example, you could use touchables, methods of demonstrating the object or for creating it, photographs and drawings of the object in its historical context, role-playing, or a question-and-answer approach.

Exercise 3. Analyze your tour and find one theme which grows out of the objects rather than depending on abstract notions such as history (e.g., a day in the life of the resident family as evidenced by the children's toys, the father's tools, and the family furniture). Go through your entire tour focusing all of your discussion on this theme. Try to discover how many ways you can reinforce this theme and still maintain interest. If you could only visit three of the exhibits (as might be necessary with a group of mentally ill individuals), decide which would be the three most instructive and comprehensible.

Emergency Procedures

In an emergency, follow procedures already established for your building or institution. However, a mentally ill person may require additional attention in a crisis. Here are some procedures to follow in addition to standard ones.

If the mentally ill person becomes confrontational:

- It is not likely that a mentally ill person will lose control of himself while at your site. However, should this happen, it is important to know how to handle the situation in order to protect yourself, the individual, and others. Remember—first and foremost—to stay calm and keep the rest of the group the same way. If a family member, friend, or group leader is available, let him take over. If you are without assistance, let the mentally ill person know that you want him to try to regain control. Give him time to quiet down. Do not make physical contact with the individual (such as putting your arm around the person's shoulder) or try to carry on a conversation with him. He may be frightened and disoriented. Call a security guard for assistance, if necessary. Disperse any crowds that gather as they only exacerbate an already bad situation.

If the mentally ill person has a seizure:

A seizure is a neurological malfunction involving an uncontrolled electrical reaction in the brain. This temporary change in functioning causes an unusual level of electrical energy to pass between cells, overloading a part or all of the brain's system. A seizure may involve muscle convulsions, partial or total loss of consciousness, mental confusion, and loss of control of some bodily functions.

There are two types of seizures, convulsive and nonconvulsive. Convulsive seizures are easier to recognize and require more assistance. The primary characteristics of a convulsive seizure are a loss of consciousness and muscle jerks.

The most important thing to remember if someone has a convulsive seizure is not to panic—remain calm and follow these basic rules:

- Place a folded coat under the person's head to prevent him from hitting it on the floor.
- Try to protect the person from hitting objects or furniture around him, but do not restrain him. The seizure must run its course.
- Loosen his tie or shirt collar and try to turn him on his side to keep his air passage clear.
- *Do not* put hard objects into his mouth or try to hold his tongue—he cannot swallow his tongue, but he can damage his teeth or your fingers by biting down forcefully.
- Do not try to get the person to drink anything during or right after the seizure.

If possible, check the person's wrists or neck for medic alert identification. If he is wearing any, it indicates the presence of a medical condition that may be related to his present physical state. It may be necessary to contact trained personnel for further assistance.

For more complete information on convulsive or nonconvulsive seizures, see the Seizure Identification

Chart provided in the Resources section at the end of this manual.

If the mentally ill person is injured:

- Carefully estimate the extent of the injury. Do not rely completely on the person's own evaluation of his injury; some mentally ill persons either exaggerate or underestimate the extent of their injuries.
- Be clear when telling the person what is happening. A person who has difficulty processing information under normal circumstances will have even more trouble in stressful situations.

If the building must be evacuated:

- Seek out the mentally ill individual and make sure he knows there is an emergency.
- Assist him in finding his way out of the building. Without such help, someone who reacts strongly to overstimulation might freeze in this situation.
- Give directions to people in several modes—orally, visually, and even tactually, if necessary.

Reference Notes

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9

People with Severe Communication Disabilities

Autism

Autism is a relatively rare, organically based (as opposed to psychologically based) syndrome that has confounded professionals since it was first identified in 1943 by Dr. Leo Kanner. It is defined by its symptoms, all of which may or may not be present in any one individual diagnosed as having autism, and it is frequently confused with mental retardation and schizophrenia. There is no known cause or cure for this disability.

Effects of the Disability

The following definition is reprinted from the membership pamphlet of The National Society for Children and Adults with Autism.

Autism is a severely incapacitating lifelong developmental disability which typically appears during the first three years of life. It occurs in approximately fifteen out of every 10,000 births and is four times more common in boys than girls. It has been found throughout the world in families of all racial, ethnic and social backgrounds. No known factors in the psychological environment of a child have been shown to cause autism.

The symptoms are caused by physical disorders of the brain. They include:

1. Disturbances in the rate of appearance of physical, social, and language skills.

2. Abnormal responses to sensations. Any one or a combination of sight, hearing, touch, pain, balance, smell, taste, and the way a child holds his body are affected.

3. Speech and language are absent or delayed while specific thinking capabilities may be present.

4. Abnormal ways of relating to people, objects and events.

Autism occurs by itself or in association with other disorders which affect the function of the brain such as viral infections, metabolic disturbances, and epilepsy. On IQ testing, approximately 60% have scores below 50, 20% between 50 and 70, and only 20% greater than 70. Most show wide variations of performance on different tests and at different times.

Autistic people live a normal life span. Since symptoms change, and some may disappear with age, periodic re-evaluations are necessary to respond to changing needs.

The severe form of the syndrome may include extreme self-injurious, repetitive, highly unusual and aggressive behaviors.

Special education programs using behavioral methods have proved to be the most helpful treatment.

Adapting Your Tour

You will probably not meet many individuals with autism on your tours. Those who do visit your facility will most likely come with family or friends, or in a group from a day school program or residential facility. The following adaptations will contribute to the success of your program and make it more enjoyable for you and your audience.

Find Out about Visitors' Interests Ahead of Time

If you know that an individual or group of people with autism is planning a visit, find out all you can about what they would like to see. People with autism often have special abilities for—or an avid interest in—subjects that are technical, mechanical, and/or music-related. Try to spark their interest in your program by offering both concrete information and participatory activities related to these or other subjects.

Prepare Pretour Materials

Send them to the group or family member who will be accompanying the autistic individual. Include as many photographs of site landmarks and important objects as possible. Most individuals with autism can comprehend objects more easily than symbols; therefore, artifacts and photographs are more desirable than written material. Also, photographs will best prepare these individuals for the unfamiliar environments and objects of your site, and later will remind them of what they have seen. Encourage group leaders and family members to use this information to prepare the individual for his visit.

Keep Tour Groups Small

This is particularly important if the audience is made up of autistic children. Depending on the severity of the individuals' disabilities, one nondisabled adult should be present for every one or two autistic children or for every five autistic adults. Avoid being alone with an autistic child; he may decide to test you and create an unpleasant situation.

Try to Keep Your Presentation Short

It should last about twenty to thirty minutes and be limited to one or two concrete ideas.

Plan a Tightly Structured Program with Limited Distractions

If possible, introduce yourself and discuss tour related materials in a quiet room with limited visual stimuli. Next, go to the exhibition area and point out the objects just discussed. Finally, go back to the quiet room for a review or end the tour and direct the group out of the facility. Avoid sudden or loud noises and overly bright lights; these can be disturbing and can trigger negative reactions in some individuals.

Make Your Activity Directions Brief and Concise

Many individuals with autism have difficulty comprehending and retaining information (although they often have good rote memories, they may be unable to generalize and correctly apply the information) and easily lose interest if asked to process too much at one time. It is best to demonstrate and solicit imitation with, "Try this."

Don't Assume Responsibility for Behavior Management

Explain to the parents or group leaders that they are responsible for any behavior management that is necessary. Then refrain from intervening if a problem arises. Some behavior management techniques appear to be very strict. Be assured that they are appropriate and have a distinct purpose. If you have questions about these techniques, never ask them in front of the autistic individual.

Try to Keep Visitors' Attention Focused on You

Don't be insulted if the autistic individuals you are addressing do not appear to be paying attention. They may be watching you with their peripheral vision or with darting glances. Try to maintain eye contact whenever possible and specifically draw attention to yourself or objects with expressions like, "Look here" or "Watch me do this."

Do Not Respond to Inappropriate or Embarrassing Remarks

Learning to behave in a socially acceptable manner is very difficult for autistic persons. Regardless of the degree of autism, one of the most frequently seen symptoms of the disability is inappropriate social response and interaction. Do not stare or draw attention to peculiar or self-abusive behavior they may exhibit and over which they have no control.

Encourage Participation in Your Tour

Most people with autism respond best to activities that involve their senses of touch, smell, or taste. Include auditory and visual stimulation also. Many autistic individuals filter out certain senses, so use the "buckshot" approach: try to reach all of the senses in the hopes of getting through to at least one. Include objects that can be held or manipulated, however, consult first with

the instructor or parent to ensure that the individual is capable of handling objects without being destructive.

Avoid the Question-and-Answer Approach

This is the least effective method of encouraging the participation of autistic individuals. Approximately twenty-five to fifty percent of individuals with autism remain nearly or totally nonverbal all of their lives. Those who do learn to use speech often have problems with grammar, pronoun reversals (saying *you* when they mean *I*), articulation, and intonation. Some people have echolalic speech only; they repeat, either immediately or at a later point, exactly what they heard regardless of whether or not it is appropriate. Even individuals with good language abilities have difficulty engaging in spontaneous conversations. Therefore, if you depend strictly on spoken language during your tour, the autistic individual may be unable to actively participate.

Be Prepared to Work with an Interpreter

Some individuals with autism who are nonverbal use sign language. The interpreter will probably be provided by the autistic person's family or group because many autistic persons are bothered by the introduction of new people. Therefore, an interpreter who is familiar to the person and knows his language ability is preferable. (For additional information, see the section on working with interpreters in the chapter on hearing impairments.)

Emergency Procedures

In an emergency, follow procedures already established for your building or institution. However, a person with autism may require additional attention in a crisis. Here are some procedures to follow in addition to standard ones.

If the person with autism is injured:

- Carefully estimate the extent of the injury. Many persons with autism will not be able to accurately assess the extent of their injuries.
- Be clear when telling the person what is happening. (A person who already has difficulty processing information will have even more trouble in a stressful situation.)

If the building must be evacuated:

- Seek out the individual with autism and make sure he knows there is an emergency. Autistic persons, particularly children, have a poor concept of what is dangerous. Make sure someone who knows the person assists him during the evacuation and remains with him.
- If the autistic person gets separated from his companion, assist him in finding his way out of the building. (Someone who reacts strongly to overstimulation might freeze in this situation.) Use verbal, visual, and tactile cues to help him get out.

Hearing-Vision Impairment

Many people know a little about hearing-vision impairment from stories of Helen Keller; however, Ms. Keller was not a typical hearing-vision impaired individual (if there *is* such a being) and her story in "The Miracle Worker" has led many to misunderstand the disability. Few of those said to be hearing-vision impaired have—as Helen Keller did—profound deafness and complete blindness, wild behavior during childhood, the natural talents of a public speaker, and the aid of a constant companion. Individuals with a hearing-vision impairment, like other people, are much more varied in their abilities and disabilities.

According to Gallaudet College, there are approximately 734,275 individuals in the United States who are both hearing impaired and visually handicapped. Of that number, 41,859 people are categorized as deaf-blind, having no usable residual hearing or vision. The remaining number of people have some residual hearing and/or sight but are impaired severely enough in both senses to experience significant problems with communication and mobility. Because the hearing impairment and visual handicap compound each other's effects, programs and services for people with either disability are not fully appropriate for those with both.

This disability can be caused by maternal illness during pregnancy (e.g., rubella), genetic factors (e.g., Usher's Syndrome), accident, or illness (e.g., spinal

meningitis). It can occur at any time in life, from birth to advanced age. Both disabilities may occur at once or one may occur years before the other; both disabilities may remain stable at one level or one may be stable while the other progressively worsens. For example, deaf people may gradually lose their sight to Usher's Syndrome (a hereditary condition that compounds a profound congenital hearing loss with a progressive deterioration of the retina that can happen at any age), cataracts, or glaucoma, among others. Blind people may become hearing impaired due to a variety of causes including presbycusis (nerve damage caused by the aging process) or otosclerosis (bone disease in the ear). The combination of many factors—severity, chronology, etiology, educational and experiential backgrounds, and/or additional disabilities—greatly affect how a hearing-vision impaired person deals with his environment.

Effects of the Disability

Communication

Communication is a major environmental concern that is affected by the degree of severity and time and order of appearance of the hearing impairment and visual handicap. There is no language designed to be communicated tactually, so hearing-vision impaired people must use methods perhaps better suited for those with single disabilities. If a person who is either hearing impaired or visually handicapped becomes hearing-vision impaired during his teenage or adult years, he already has an established mode of communication—speech or sign language—that he must adapt or abandon because of the needs of the new dual disability. However, if he has had this multiple disability from birth or early childhood, he probably learned early on a communication method that best utilizes his sensory abilities and matches his personality type.

Methods of communication used by people with hearing-vision impairment include:

Sign language. This form of communication is used both receptively and expressively. To receive information, a hearing-vision impaired individual might stand close to the speaker in order to see the signs more clearly, or place his hands onto the signer's hands to read the information, or combine the two methods.

Fingerspelling. This common method of communication for hearing-vision impaired people involves spelling out manually each letter of a word. The person receiving the communication can feel handshapes in one of three ways: by placing his hand over the top of the speaker's hand; by placing his hand under the speaker's hand so that the fingerspelling points down into his palm; or by circling both hands around the fingerspelling hand (this is called, appropriately, the "Bird Cage" method). Fingerspelling is a much slower, but often the more accurate, method of communication than signing or speaking (one can fingerspell a maximum of 60 words per minute while one can speak at a rate of 150 words per minute).

Use of an interpreter. Because most people are not proficient in sign language or fingerspelling, many hearing-vision impaired people prefer to use the services of an interpreter. A one-to-one situation (one hearing-vision impaired person to one interpreter) is usually necessary for people who need either signing at close range or fingerspelling/signing by touch. An interpreter for people with hearing-vision impairment may be asked to give information about the surroundings, such as the color, size, and shape of objects or rooms and the action taking place in a movie or stage production.

Speech. Like sign language, speech is also used for both receptive and expressive communication. An individual who is hard of hearing may have the speaker talk directly into his ear, while an individual who is profoundly hearing impaired may use the Tadoma Method and lipread by placing his hand lightly on the speaker's throat and face to feel the vibrations, mouth movements, and breath flow from his speech.

Written material. Many hearing-vision impaired people can read large-print type or hand-printed information written with a dark-colored ink pen. Communication may then take place through notes passed back and forth.

Palm printing. Block letters (capitals only) may be traced—one at a time—onto the palm of a hearing-vision impaired individual's hand. To indicate breaks, there should be pauses between words and sentences, or the person's hand can be tapped once at the end of each word and twice at the end of each sentence. Cueing systems such as these should be set up with each individual before communication begins. (For more information, see the supplemental section on how to palm print at the end of this chapter.)

Hearing-vision impaired people may also use other methods of communication, such as Morse Code and braille; therefore, it is very important to find out which is their preferred method before beginning.

Interpersonal Relationships

A major consequence of this disability seems to be isolation. Communication with hearing-vision impaired people can be difficult and time consuming, and they may be left out of conversations entirely or included for one or two sentences only. Many nondisabled people do not know how to approach a hearing-vision impaired person and may avoid contact altogether. Deaf or blind people also avoid contact, either because the individual with the hearing-vision impairment separates himself from them or because they feel uncomfortable with someone who is experiencing the fate they fear—not having the other sense.

Another concern that sometimes increases a hearing-vision impaired person's isolation is mobility. Many people, including those who are hearing impaired or visually handicapped, question the hearing-vision impaired person's ability to get around and are reluctant to take on responsibility for him. Actually, people with a hearing-vision impairment may travel independently or use a cane, a dog guide, or sighted guide, depending on their personality and degree of disability. They are usually very capable of traveling and participating in sports or other activities. (For more information on mobility aids, see that section in the chapter on visual handicaps.)

Because hearing-vision impaired people are often excluded from everyday social and recreational activities in which they could easily participate, they often feel lonely and isolated. The unnecessary limits often placed on these people only compound their disabilities and further narrow their experiences.

Adapting Your Tour

Communicate Directly with the Hearing-Vision Impaired Individual

It is likely that the hearing-vision impaired person will visit your museum either in a group or with a companion. He may or may not bring an interpreter. Regardless of whether or not he is with a companion or interpreter, always speak directly to him. Before you start your tour, approach the individual and touch him on the hand to let him know you are there. Introduce yourself by speaking through an interpreter if one is present. If the individual is alone, introduce yourself by palm printing, fingerspelling into his hand, or—if the person has residual vision—by printing a message on paper with a dark-ink pen. (If the person has little or no residual vision and hearing, he will probably turn to you and put out his hand for more information. Palm printing or fingerspelling into his hand would be appropriate modes to begin communication. If the person has usable vision or hearing, he will probably turn to you and wait expectantly. Begin speaking clearly and show him your preprinted message.) Find out which mode of communication he prefers and allow enough time for information to reach him (i.e., if he uses fingerspelling it will take longer to communicate than if he uses sign language). Always let him know you are leaving before you walk away.

Offer to Assist the Hearing-Vision Impaired Individual

Some hearing-vision impaired people have balance problems and need extra support on staircases, uneven walking surfaces, and in crowded areas. Stand behind a hearing-vision impaired person when ascending an escalator and in front of him when descending it. Use the same technique for guiding people on and off an escalator that you would use with visually handicapped visitors. (For more information on sighted guide techniques, see the supplemental section in the chapter on visual handicaps.)

Select Quiet, Well-Lighted Areas of the Museum

On a tour, people with residual sight and/or hearing benefit most from this type of situation. Well-lighted areas serve to aid mobility and make reading sign language easier.

Encourage Participation in Your Tour

Be sure that the hearing-vision impaired person is included in the tour discussion. Encourage questions from the entire group without overlooking the person with hearing and visual impairments as a discussion participant. Remember that it may take longer to communicate information to this individual, so he may be slower to respond.

Present As Many Touchable Objects As Possible

If an artifact cannot be touched, use secondary or related objects, accurate models, or raised-line drawings. Be sure to tell the person that you are not using the actual artifact and why; also explain how the substitute and the original are alike and different. If touchables are not available, describe the objects in great detail. (For information on how to describe objects, see

that section in the chapter on visual handicaps. For additional suggestions on tour adaptations, refer to the chapters on hearing impairments and visual handicaps.)

Emergency Procedures

In an emergency, follow procedures already established for your building or institution. However, a hearing-vision impaired person may require additional attention in a crisis. Here are some procedures to follow in addition to the standard ones.

If the hearing-vision impaired person is injured:

- You or someone else (e.g., the interpreter) should stay with the hearing-vision impaired person throughout a museum or personal emergency. Don't abandon the person or expect him to figure out for himself what is happening.

If the building must be evacuated:

- Make the hearing-vision impaired person aware of the emergency. Communicate the information as efficiently as possible. If you do not know which system he uses, try several methods, including gestures. Make sure that the person knows what to do.
- Escort the person or group out through the nearest exit. If you have to move the person suddenly, explain what you were doing as soon as possible. Don't let the person with a hearing-vision impairment think that he has done something wrong or that you are trying to get rid of him.

(For other suggestions concerning emergency procedures, refer to the appropriate sections in the chapters on hearing impairments and on visual handicaps.)

Other Multiple Disabilities

Today there are more people with multiple disabilities than ever before. This is because children born with more than one impairment or who have severe illnesses during their early years are now surviving; new medications capable of curing some of those diseases can cause permanent disabilities; and since people are now living longer, they are likely to experience disabilities caused by the aging process. Your chances of meeting people with more than one disability are becoming greater every day.

There are many possible combinations of disabilities and severity levels. Some people with multiple disabilities will have problems with communication (e.g., those who are blind and mentally retarded or deaf and have cerebral palsy); others will not. Therefore, each person with multiple disabilities presents an almost unique situation. Try to find out which disabilities are involved and which program adaptations are appropriate. Then draw information from the appropriate chapters in this manual.

Supplemental Information

Palm Printing with Hearing-Vision Impaired People

Reference Notes

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10

Older Adults

The "older adult boom" is going strong. People who are sixty-five years old and older are part of the fastest growing segment of the U.S. population, according to statistics from the American Association of Retired Persons. In 1983 there were 27.4 million people (11.7 percent of the population) over the age of sixty-five. This constituted a six percent increase in the growth rate of the older adult group from 1980 to 1983, as opposed to a three percent increase during the same period in the number of those under sixty-five. At this rate, the older population will reach sixty-five million (21.2 percent of the population) by the year 2030. These significant figures emphasize the importance of learning more about older adults and their changing needs; they may soon become the majority of the visitorship in museums.

It is important to remember that although most older adults are not disabled, approximately twenty percent of the population over the age of sixty-five has some degree of disability. Therefore, much of the information on people with adventitious disabilities (those that occurred after birth) will apply to this segment of the population.

Of that remaining eighty percent who are not disabled, many experience sensory changes that affect their ability to fully enjoy museums. While these people may not need specific assistance, they can benefit by your understanding their needs and offering subtle adapations to your tours. If you have a group of older adults visiting your site, its members will probably have mixed levels of abilities and disabilities. For this group more than any other, you must make your programs as accessible as possible to the widest possible public.

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Sensory Changes in Older Adults: Implications for Museums

by Tamerra P. Moeller

Individuals 75 or more years old compose the fastest growing age group in the United States.[1] All of these individuals experience sensory changes, and increasing amounts of research are directed toward understanding ways in which interior and exterior environments can be adapted to accommodate those changes.[2,3,4,5] In addition, data need to be collected on the interaction of sensory systems, for these interactions provide the background for the older person's behavior and adaptation. Generally, sensory data have been collected with reference to a single system; however, as one sense becomes less acute in the later years, compensation will occur with another. Decreased hearing ability will be accompanied by increased visual attention to lip movements and facial expressions. This type of compensation is one of the most important processes in the later years, yet one of the least studied.

Normal Visual Changes in the Later Years

The visual system continues to change throughout life. Although most older people have adequate and even good vision, both the structure of the eye and the processing of visual information are altered by the passage of time. Normal changes in the pupil and the lens have significant ramifications upon the performance of daily activities by older persons.

In the later years, the size of the pupil tends to decrease. It has been estimated that approximately

one-third less light reaches the retina in the older eye as compared to the amount of light reaching the retina in a younger eye. The decreased size of the pupil diminishes the older person's ability to function in lowered light levels and to see at night.[6] Restaurants, theaters, dimly lit waiting rooms, and outside areas in the evening create particularly difficult situations.[7,8] The older person also has problems adjusting to changes in the level of lighting. Accidents are more likely to occur, and, consequently, areas that bridge two different levels of illumination should be free of potential barriers. Overall, more uniform lighting would permit easier and safer negotiation of the environment.

Several changes are also noticeable in the lens of the eye as early as the mid-forties. The optic muscle becomes less capable of contracting the lens in order to focus on objects close to the eye. Also, although the research is not yet conclusive, changes in the lens and optic muscles may also decrease the rapidity with which the older eye can change focus. Further, by the age of 65, the visual acuity of nearly half the population is 20/70 or poorer. Visual acuity can be corrected by glasses but not necessarily to produce 20/20 vision. In recent years, there has been an increasing interest in the development of low-vision clinics to serve those individuals whose corrected vision falls between 20/70 and 20/200.[9]

Another change in the lens is its increased density in the later years. As a person ages, the light entering the lens is more likely to scatter, creating problems with glare. With increasing glare, the cooler colors (blues and greens) often appear to fade more than the warmer colors (reds, yellows, oranges, pinks and browns). Cooler colors have shorter wave lengths and warmer colors have longer wave lengths. The shorter wave lengths of the cooler colors are absorbed more by the lens, and the longer ones of the warmer colors are more likely to pass through the older adult's increasingly dense lens to the retina. The edges of stairs, platforms, counter tops, and porches need to be delineated as well as the rims of plates, glasses and trays. The colors chosen to define these edges should contrast with their background in both shade and intensity. The white background of traffic signs, labels, prescriptions, and other products create glare. Glossy paper produces more glare for the older reader than for the younger one. High gloss linoleum can turn a hallway into a dangerous passageway in a very bright light, and the placement of mirrors must be handled so as to diminish the glare that may occur if a mirror is in direct light.

Overall, there is an urgent need to evaluate environments in terms of the clarity of visual information, such as signs, steps and curbs. Not only are safety and independence influenced by the quality of lighting and the delineation of boundaries, but esthetic pleasure and the sense of well-being are also enhanced in a well-designed space.

Normal Hearing Changes in the Later Years

Hearing loss is one of the most frequent impairments encountered by older people.[10] Difficulties in hearing can lead to feelings of suspicion, depression, and withdrawal. Three types of hearing loss are often found in the later years. Conductive hearing loss, the result of an outer or middle ear blockage, which can usually be corrected, occur most frequently because of wax in the outer ear or infections in the middle ear. The older person with this problem hears all sounds less distinctly. Voices become muffled, and the location of noises is unclear.

A second type of hearing loss is a sensory impairment, or presbycusis, which is thought to originate in the inner ear. A person who suffers from presbycusis has unusual difficulty in perceiving and distinguishing high tones, although all tones may be less distinct. Since most consonants are high tones, comprehension of speech may become quite difficult. It is this type of sensory loss for which hearing aids are prescribed; however, adjustment to a hearing aid is often difficult because hearing is not restored to normal. Many sounds are amplified, and the user must become accustomed to "hearing" in the presence of amplified background noise.[11]

A third type of hearing loss has been more generally recognized only within the last ten years. Often labeled as a sensory neural hearing deficit, this problem occurs in the transmission of sound along the auditory nerve between the inner ear and the brain. A person with this problem may be able to hear every word but not comprehend the message, particularly if it is delivered in a rapid manner; conversations involving several people are confusing to follow, and the presence of background noise further reduces comprehension. Slower speech, the use of moderate voice tones, distinct enunciation and the reduction of background noise are helpful to individuals with this and other types of hearing problems.[12]

Normal Changes in Taste and Smell

The sense of taste and smell determine, in large part, the flavor of food and beverages. The sense of taste informs a person of the sweetness, saltiness, sourness, and bitterness of foods. Another part of the taste and

smell system is a nerve which provides information about the warmth, coolness, and pungency of inhaled vapors and ingested foods. The heat of hot peppers, the coolness of menthol, and the bite of horseradish are signaled by this nerve.

During normal aging, many individuals experience less chemosensory sensation. Anatomical studies show that from early life onward the number of fibers in the olfactory nerve tends to decrease. The older person may not be as able to identify offensive odors and may not be as aware of them. The decline in taste sensitivity may occur after the age of 50 but is more prevalent after the age of 70. For many older persons, taste buds at the front of the tongue that are sensitive to sweet and salty flavors seem to atrophy first, but the bitter and sour buds function well into an individual's 70s.[13]

For those who experience taste loss in later years, the enjoyment of food and odors can be increased through use of contrasting colors and textures. Spices, herbs, and other flavorings such as garlic, cloves, onion, and cinnamon enhance the flavor of food. Well-seasoned food results in increased dietary variety and intake and ultimately contributes to better nutrition.

The Sense of Touch

Recent findings indicate that the sense of touch apparently is well preserved. Healthy older individuals differ little from younger persons in sensitivity to passive touch stimulation, with the exception of the vibratory sense on the bottom of the foot. With respect to active touch, there may be a slight reduction in the older person's ability to distinguish, for example, two grades of sandpaper; however, the decrease is thought to be relatively minimal. Older people are able to feel and to enjoy physical contacts; however they are the least touched individuals in mainstream American society. Furthermore, intimate human contact between older people is portrayed by the media in derogatory, stereotypic ways. Certainly, a new image of the older person as a feeling, sensitive human being is long overdue.[14]

Implications for the Older Person's Involvement in Museums

As the older population continues to expand, it will become increasingly important for museum personnel to adapt both programming and the physical surroundings. Older people will benefit greatly from a museum environment which reflects sensitivity to their changing senses.

In the area of programming, lecturers should be encouraged to speak at a moderate pace with distinct enunciation. Any printed material should have large print against a non-glare background, and the color of the print should contrast with the paper on which it is printed. Black print on a beige or off-white background or red print on a yellow background would be preferable to blue print on a green background, as the cooler colors tend to fade together.

The physical environment may be improved by the provision of bright but diffuse lighting, the marking of edges of curbs, stairs and protrusions, as well as signs which contain large, uncrowded print. In addition, the announcement of messages for visitors in the museum should be given in clear, distinct tones with little background noise, such as music, when a verbal message is being given.

Inservice training should be provided to all museum staff on the sensory changes older people experience and the implications of these changes. Frequently, the slowness with which an older person may respond is mistakenly identified as declining mental capacity rather than difficulty, for example, in receiving a message which is given too quickly in the presence of considerable background noise. Museum staff should operate with an understanding of the normal sensory changes of older adults.

Notes

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In addition to sensory changes, older adults may also move more slowly and have less stamina. Almost fifty percent of older adults have arthritis, and most older adults have some degree of weakening in their muscles. Because of these changes, individuals may have difficulty standing and walking for long periods without a break. You should consider these factors when planning your tour; select a route with rest areas, restrooms, and elevators or escalators whenever possible.

Arthritis and loss of muscle strength may also affect the older adult's ability to work at activities requiring finger and hand control. Remember this when planning participatory programs involving such components as needlework or manipulation of small machine parts. Consider it also when passing around large, heavy, or awkward objects; assist by holding the object when passing it around a group or provide a surface on which to slide the object from person to person. A strong older adult then has the option of picking up the object for closer examination, while the weaker individual can enjoy it without feeling embarrassed by his inability to handle the piece.

Many older adults, even those who are not disabled, experience sensory and mobility changes that make hearing your speech or following an extended tour difficult. Keep this in mind and be prepared to subtly offer assistance if you think it appropriate.

Reference Notes

p. 79 OLDER ADULT STATISTICS: American Bankers Association and American Association of Retired Persons, *Older Bank Customers: An Expanding Market Participant Workbook* (Washington, D.C.: American Bankers Association, 1985), pp. 1–2.

p. 79 TWENTY PERCENT OVER SIXTY-FIVE: U.S. Senate Special Committee on Aging in conjunction with the American Association of Retired Persons, the Federal Council on Aging, and the Adminstration on Aging, *Aging America: Trends and Projections*, 1985–86 ed. (Washington, D.C.: Government Printing Office, 1986), no page.

p. 79 SENSORY CHANGES IN OLDER ADULTS: T. P. Moeller, "Sensory Changes in Older Adults: Implications for Museums," *Roundtable Reports: The Journal of Museum Education*, Fall 1984, pp. 2–11.

p. 82 FIFTY PERCENT OF OLDER ADULTS HAVE ARTHRITIS: American Bankers Association and American Association of Retired Persons, *Older Bank Customers: An Expanding Market Leader's Guide* (Washington, D.C.: American Bankers Association, 1985), p. 28.

p. 82 PLANNING PARTICIPATORY PROGRAMS: E. M. Sharpe, *The Senior Series Program: A Case Study with Implications for Adoption* (Washington, D.C.: Smithsonian Institution, 1982), pp. 58–64.

Resources

This section includes names of organizations and materials that will provide you with additional information about people with disabilities.

The first part is a chart on epilepsy, differentiating among the types of seizures and explaining the best methods of assisting someone having a seizure. This chart is located here because it applies not only to people who have epilepsy but also to those who infrequently have seizures which may be related to cerebral palsy, mental retardation, or mental illness.

Part two alphabetically lists agencies that serve disabled individuals. You can contact these groups for technical and staff training assistance.

The final part is a selected bibliography, arranged by chapter in this manual. The texts listed, easy to obtain in bookstores and through organizations listed in the second section, offer nontechnical, practical information about people with disabilities.

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Seizure Identification Chart

Seizure Type	What It Looks Like	Often Mistaken For	What To Do	What Not To Do
Convulsive Generalized Tonic-Clonic (Also called Grand Mal)	Sudden cry, fall, rigidity, followed by muscle jerks, frothy saliva on lips, shallow breathing or temporarily suspended breathing, bluish skin, possible loss of bladder or bowel control, usually lasts 2-5 minutes. Normal breathing then starts again. There may be some confusion and/or fatigue, followed by return to full consciousness.	Heart attack. Stroke. Unknown but life threatening emergency.	Look for medical identification. Protect from nearby hazards. Loosen ties or shirt collars. Place folded jacket under head. Turn on side to keep airway clear. Reassure when consciousness returns. If single seizure lasted less than 10 minutes, ask if hospital evaluation wanted. If multiple seizures, or if one seizure lasts longer than 10 minutes, take to emergency room.	Don't put any hard implement in the mouth. Don't try to hold tongue. It can't be swallowed. Don't try to give liquids during or just after seizure. Don't use oxygen unless there are symptoms of heart attack. Don't use artificial respiration unless breathing is absent after muscle jerks subside, or unless water has been inhaled. Don't restrain.
Non-Convulsive Absence (Also called Petit Mal)	A blank stare, lasting only a few seconds, most common in children. May be accompanied by rapid blinking, some chewing movements of the mouth. Child having the seizure is unaware of what's going on during the seizure, but quickly returns to full awareness once it has stopped. May result in learning difficulties if not recognized and treated.	Daydreaming. Lack of attention. Deliberate ignoring of adult instructions.	No first aid necessary, but medical evaluation should be recommended.	

Seizure Type	What It Looks Like	Often Mistaken For	What To Do	What Not To Do
Non-Convulsive Simple Partial (Also called Jacksonian)	Jerking begins in fingers or toes, can't be stopped by patient, but patient stays awake and aware. Jerking may proceed to involve hand, then arm, and sometimes spreads to whole body and becomes a convulsive seizure.	Acting out, bizarre behavior.	No first aid necessary unless seizure becomes convulsive, then first aid as above.	
Non-Convulsive Simple Partial (Also called Sensory)	May not be obvious to onlooker, other than patient's preoccupied or blank expression. Patient experiences a distorted environment. May see or hear things that aren't there, may feel unexplained fear, sadness, anger, or joy. May have nausea, experience odd smells, and have a generally "funny" feeling in the stomach.	Hysteria. Mental illness. Psychosomatic illness. Parapsychological or mystical experience.	No action needed other than reassurance and emotional support.	

Seizure Type	What It Looks Like	Often Mistaken For	What To Do	What Not To Do
Non-Convulsive Complex Partial (Also called Psychomotor or Temporal Lobe)	Usually starts with blank stare, followed by chewing, followed by random activity. Person appears unaware of surroundings, may seem dazed and mumble. Unresponsive. Actions clumsy, not directed. May pick at clothing, pick up objects, try to take clothes off. May run, appear afraid. May struggle or flail at restraint. Once pattern established, same set of actions usually occur[s] with each seizure. Lasts a few minutes, but post-seizure confusion can last substantially longer. No memory of what happened during seizure period.	Drunkenness. Intoxication on drugs. Mental illness. Indecent exposure. Disorderly conduct. Shoplifting.	Speak calmly and reassuringly to patient and others. Guide gently away from obvious hazards. Stay with person until completely aware of environment. Offer to help getting home.	Don't grab hold unless sudden danger (such as a cliff edge or an approaching car) threatens. Don't try to restrain. Don't shout. Don't expect verbal instructions to be obeyed.
Non-Convulsive Atonic Seizures (Also called Drop Attacks)	The legs of a child between 2-5 years of age suddenly collapse under him and he falls. After 10 seconds to a minute he recovers, regains consciousness, and can stand and walk again.	Clumsiness. Lack of good walking skills. Normal childhood "stage."	No first aid needed (unless he hurt himself as he fell), but the child should be given a thorough medical evaluation.	

Seizure Type	What It Looks Like	Often Mistaken For	What To Do	What Not To Do
Non-Convulsive Myoclonic Seizures	Sudden brief, massive muscle jerks that may involve the whole body or parts of the body. May cause person to spill what they [sic] were holding or fall off a chair.	Clumsiness. Poor coordination.	No first aid needed, but should be given a thorough medical evaluation.	
Non-Convulsive Infantile Spasms	Starts between 3 months and two years. If a child is sitting up, the head will fall forward, and the arms will flex forward. If lying down, the knees will be drawn up, with arms and head flexed forward as if the baby is reaching for support.	Normal movements of the baby, especially if they happen when the baby is lying down.	No first aid, but prompt medical evaluation is needed.	

Resource Agencies

Alexander Graham Bell Association for the Deaf
The Volta Bureau
1537 35th Street, N.W.
Washington, D.C. 20007
(202) 337-5220 (voice and Telecommunications Device for the Deaf—TDD)

American Association of the Deaf-Blind, Inc.
c/o Hearing-Vision Impaired Programs
Gallaudet University
College for Continuing Education
800 Florida Avenue, N.E.
Washington, D.C. 20002
(202) 651-5242 (voice and TDD)

American Association on Mental Deficiency
1719 Kalorama Road, N.W.
Washington, D.C. 20009
(202) 387-1968

American Association of Retired Persons
1909 K Street, N.W.
Washington, D.C. 20006
(202) 872-4700

American Council of the Blind
1010 Vermont Avenue
Suite 1100
Washington, D.C. 20005
(202) 393-3666
1-800-424-8666 (outside the District of Columbia)

American Deafness and Rehabilitation Association
Deaf-Blind Section
814 Thayer Avenue
Silver Spring, Maryland 20910
(301) 589-0880 (voice and TDD)

American Foundation for the Blind
15 West 16th Street
New York, New York 10011
(212) 620-2000

American Optometric Association
600 Maryland Avenue, S.W.
Suite 400
Washington, D.C. 20024
(202) 484-9400

American Printing House for the Blind
P.O. Box 6085
Louisville, Kentucky 40206
(502) 895-2405

American Speech, Language, and Hearing Association
10801 Rockville Pike
Rockville, Maryland 20852
(301) 897-5700 (voice and TDD)

Arthritis Foundation
1314 Spring Street, N.W.
Atlanta, Georgia 30309
(404) 872-7100

Association for Children with Learning Disabilities
4156 Library Road
Pittsburgh, Pennsylvania 15234
(412) 341-1515

Association of Learning Disabled Adults
P.O. Box 9722
Friendship Station
Washington, D.C. 20016

Better Hearing Institute
5021 B Backlick Road
Annandale, Virginia 22003
(703) 642-0580

Centers and Services for Deaf-Blind Children
Office of Special Education
U.S. Department of Education
400 Maryland Avenue, S.W.
Stop #2313-3094
Washington, D.C. 20202
(202) 732-1177

Council for Exceptional Children
1920 Association Drive
Reston, Virginia 22091
(703) 620-3660

Disabled American Veterans
807 Maine Avenue, S.W.
Washington, D.C. 20024
(202) 554-3501

Epilepsy Foundation of America
4351 Garden City Drive
Landover, Maryland 20785
(301) 459-3700

Hadley School for the Blind
700 Elm Street
Winnetka, Illinois 60093
(312) 446-8111

Hearing-Vision Impaired Programs
College for Continuing Education
Gallaudet University
College Hall Room 217
800 Florida Avenue, N.E.
Washington, D.C. 20002
(202) 651-5242 (voice and TDD)

Helen Keller National Center for Deaf-Blind Youth and Adults
111 Middle Neck Road
Sands Point, New York 11050
(516) 944-8900 (voice and TDD)

John Tracy Clinic
806 West Adams Boulevard
Los Angeles, California 90007
(213) 748-5481

Joseph P. Kennedy, Jr. Foundation
1350 New York Avenue, N.W.
Suite 500
Washington, D.C. 20005
(202) 393-1250

Muscular Dystrophy Association, Inc.
1625 Eye Street, N.W.
Suite 922
Washington, D.C. 20019
(202) 838-5508

National Alliance for the Mentally Ill
1901 North Fort Myer Drive
Suite 500
Arlington, Virginia 22209
(703) 524-7600

National Association of the Deaf
814 Thayer Avenue
Silver Spring, Maryland 20910
(301) 587-1788 (voice and TDD)

National Association for Retarded Citizens
2501 Avenue J
Arlington, Texas 76006
(817) 640-0204

National Captioning Institute, Inc.
5203 Leesburg Pike, 15th Floor
Falls Church, Virginia 22041
(703) 998-2400 (voice and TDD)
1-800-336-3444

1443 Beachwood Drive
Hollywood, California 90028
(213) 469-7000

545 5th Avenue, 8th Floor
New York, New York 10017
(212) 557-7011

National Council on the Aging, Inc.
600 Maryland Avenue, S.W.
West Wing 100
Washington, D.C. 20024
(202) 479-1200

National Council of Senior Citizens
925 15th Street, N.W.
Washington, D.C. 20005
(202) 347-8800

National Easter Seal Society
2023 West Ogden Avenue
Chicago, Illinois 60612
(312) 243-8400

National Federation of the Blind
National Center for the Blind
1800 Johnson Street
Baltimore, Maryland 21230
(301) 659-9314

National Information Center on Deafness
Gallaudet University TE6
800 Florida Avenue, N.E.
Washington, D.C. 20002
(202) 651-5052 (voice and TDD)

National Institute of Mental Health
Public Inquiries
5600 Fishers Lane
Rockville, Maryland 20857
(301) 433-4515

National Institute of Neurological and Communicative Disorders and Stroke
NIH-NINCDS Building #31
Room 8A16
Bethesda, Maryland 20892
(301) 496-5752

National Library Service for the Blind and Physically Handicapped
The Library of Congress
7826 Eastern Avenue, N.W.
Suite 410
Washington, D.C. 20012
(202) 882-5100
1-800-424-8567

National Multiple Sclerosis Society
205 East 42nd Street
New York, New York 10017
(212) 986-3240

National Society for Children and Adults with Autism
1234 Massachusetts Avenue, N.W.
Suite 1017
Washington, D.C. 20005-4599
(202) 783-0125

National Society to Prevent Blindness
79 Madison Avenue
New York, New York 10016
(212) 684-3505

National Spinal Cord Injury Association
149 California Street
Newton, Massachusetts 02164
(617) 964-0521

New York Association for the Blind
Low Vision Service
111 East 59th Street
New York, New York 10022
(212) 355-2200

The Orton Society, Inc.
724 York Road
Towson, Maryland 21204

Paralyzed Veterans of America
801 Eighteenth Street, N.W.
Washington, D.C. 20006
(202) 872-1300

Perkins School for the Blind
175 North Beacon Street
Watertown, Massachusetts 02172
(617) 924-3434 (voice)
(617) 924-5525 (TDD)

President's Committee on Mental Retardation
330 Independence Avenue, S.W.
Washington, D.C. 20201
(202) 245-7634

Recordings for the Blind, Inc.
20 Roszel Road
Princeton, New Jersey 08540
(609) 921-6534
1-800-221-4792

Registry of Interpreters for the Deaf
814 Thayer Avenue
Silver Spring, Maryland 20910
(301) 588-2406 (voice and TDD)

Self-Help for the Hard of Hearing
7800 Wisconsin Avenue
Bethesda, Maryland 20814
(301) 657-2248 (voice)
(301) 657-2249 (TDD only)

Spina Bifida Association of America
1700 Rockville Pike
Suite 540
Rockville, Maryland 20854
(301) 770-7222

Telecommunications for the Deaf, Inc.
814 Thayer Avenue
Silver Spring, Maryland 20910
(301) 589-3786 (voice)
(301) 589-3006 (TDD)

Time Out to Enjoy, Inc.
715 Lake Street
Oak Park, Illinois 60302
(312) 383-9017

United Cerebral Palsy Association
66 East 34th Street
New York, New York 10016
(212) 481-6300

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